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# LIST OF ACRONYMS

ACT	Acceptance and Commitment Therapy
Als	Adjuvant Aromatase Inhibitor Therapy
APA	American Psychiatric Association
APOS	American Psychosocial Oncology Society
ASCO	American Society of Clinical Oncology Cancer Survivorship
BPOS	British Psycho Oncology Group
BSI-18	Brief Symptom Inventory 18
CALM	Managing Cancer and Living Meaningfully
CBT	Cognitive Behavioural Therapy
CSA	Cancer Survivor Adaptation Model
DCIS	Ductal Carcinoma in Situ
DSM	Diagnostic and Statistical Manual of Mental Disorders
DT	Distress Thermometer
FSD	Female Sexual Dysfunction
FSFI	Female Sexual Functioning Index
FSI	Fatigue Symptom Inventory
GAD	General Anxiety Disorder
HADS	Hospital Anxiety and Depression Scale
HSDD	Hypoactive Sexual Desire Disorder
IBC	Inflammatory Breast Cancer
ICD-CM	International Classification of Disease- Clinical Modification
IOM	Institute of Medicine
IPA	Independent Practitioners Association
IPOS	International Psycho-Oncology Society
LCIS	Lobular Carcinoma in Situ
MBC	Metastatic Breast Cancer
MBCT	Mindfulness-Based Cognitive Therapy

MRI	Magnetic Resonance Imaging
MRM	Modified Radical Mastectomy
NCCI	National Cancer Control Initiative
NCCN	National Comprehensive Cancer Network
NCCN	National Comprehensive Cancer Network
NGS	Nottingham Grading System
NHMRC	National Health and Medical Research Council
NHMRC	National Health and Medical Research Council
NHRD	National and Provincial Health Research & Ethics Committees
NICE	National Institute of Health and Clinical Excellence
PD	Paget's Disease
PMPS	Post Mastectomy Pain Syndrome
PMS	Premenstrual Syndrome
POSON	Psycho-Oncology Society of Nigeria
PTSD	Post Traumatic Stress Disorder
RSCL	Rotterdam Symptom Checklist
SNRI	Serotonin Norepinephrine Reuptake Inhibitors
SSRI	Selective Serotonin Reuptake Inhibitors
TCAs	Tricyclic Antidepressants
TNM	Tumour Node Metastasis
WHO	World Health Organisation

# CHAPTER I:

## INTRODUCTION

### 1.1 OVERVIEW AND STATISTICS

Breast cancer is a major health risk for all women throughout the world including South Africa. According to the National Cancer Registry (2010) breast cancer is the number one malignancy amongst women of all races with a lifetime risk of 1 in 26 with approximately 5% being younger than 35 years of age (Brem & Kumar, 2011; Reyes-Gibby, Anderson & Morrow, 2012; Travado & Reis, 2013; Van Oers & Schlebusch, 2013; Wong-Kim & Bloom, 2005). Because of advances in breast cancer detection and treatment modalities in the last decade, there is a noticeably prolonged survival time for this population with survivorship after 5 years for early localized breast cancer being above 96%. There is an 82% survival rate for at least 10 years for all women diagnosed with breast cancer. These statistics make breast cancer survivors officially the largest group of cancer survivors among women in the western world (Fischer, Dolbeault, Sultan, & Bredart, 2014; Herbst, 2011; Reyes-Gibby, Anderson, Morrow, Shete & Hassan, 2012; Vorobiof, Sitas & Vorobiof, 2001).

The U.S. Census Bureau has predicted that over the next 50 years the number of cancer survivors will escalate at a larger rate than the incidence of cancer itself (Ries et al., 2008; Naus, Ishler, Parrot & Kovacs, 2009) and while these rising numbers should be celebrated, it also causes patients to live longer with possible pathological conditions resulting from the disease (Dean, 2008; Nekolaichuk, Turner, Collie & Cumming, 2012). This survivorship of the breast cancer population implies the necessity to concentrate on the unique needs of the breast cancer patient and survivor which is multifaceted and requires a shift from the biological, acute care model to a multidimensional chronic care model with a wellness component (Miles, 2009; Venter, 2014). It is the vision of the International Psycho-Oncology Society (IPOS) that all cancer patients and their families throughout the world should receive optimal psycho-social care at all stages of the disease and survivorship, pleading urgency with the behavioural and

social scientists to initiate and develop a psycho-social intervention plan as part of a holistic multidisciplinary quality care for cancer patients (Breitbart, Bultz, Dunn, Grassi & Watson, 2013).

## **1.2 BREAST CANCER AS THE MAIN SUBJECT OF THIS STUDY**

Although the incidence of survival of all types of cancers has grown noticeably in recent years (from 56% to 62%), breast cancer has become the most predominant cancer for women of all ages and races in the Western world with the highest survival rate and the second highest cause of death (Brem & Kumar, 2011; Reyes-Gibby et al., 2012; Nekolaichuk, Turner, Collie, & Cumming, 2012; Wong & Bloom, 2005). Because of the high incidence of breast cancer in South Africa and the anticipated increase in breast cancer survivors over the next few decades, this particular cancer population has become a field of interest and research within health related quality of life aspects. This field necessitates the critical need to find creative strategies to assist this population to adapt successfully to their cancer reality (Fischer et al., 2014; Greeff, 2008; Hummel, van Lankveld, Oldenburg, Hahn, Broomans, & Aaronson, 2015).

The diagnosis of any form of cancer can have a distressing impact on the psychological and sexual welfare of the patient. Going through the traumatic process of a cancer diagnosis, with an often sequential lengthy and tiring treatment process, can be biologically and psychologically exhaustive for the patient and her family (Carpenter, Andersen, Fowler & Maxwell, 2009; Katz, 2005). Although all cancers can cause psycho-pathology such as depression, anxiety and sexual dysfunction, it is evident that women with breast cancer and gynaecologic cancers have a higher risk of developing depression or other mood disorders and sexual dysfunctions compared to other cancers. The main reason for this tendency is hormonal changes due to their postmenopausal or oestrogen deficiency state, causing certain symptoms to remain long after the end of treatment which make those women good candidates for psychotherapy (Juraskova, Butow, Bonner, Robertson, & Sharpe, 2013; Phaendler, Wenzel, Mechanic & Penner, 2015). A recent study done by Fischer and colleagues, (2014) has confirmed this point by demonstrating that one in three patients who attended

counselling were women with breast cancer, as opposed to counselling for patients with colorectal, lung or prostate cancers who attended less counselling.

Comparing breast cancer with related cancers such as gynaecologic cancers, prostate and testicular cancers, shows clear resemblances in symptoms, treatments, side-effects and chronicity, as well as influences on the patient's quality of life. Another resemblance between these cancers and breast cancer is the lack of existing research and specific intervention guidelines and open communication between patients and treating practitioners concerning their emotional and sexual experiences and needs.

Working as a private clinical psychologist predominantly in a hospital environment, I am challenged on a daily basis by the different kinds of physical illnesses that affect the psychological and sexual dimensions of the patient. For the last 25 years I have worked closely with oncology patients, especially breast cancer patients, hence my interest in the dynamics of this illness. The emotional and sexual experiences of the breast cancer patient during her cancer journey and her needs and expectations related to psychotherapeutic interventions are the focus of this study. As the researcher and therapist of this study, I hope that by understanding the dynamics of breast cancer in terms of the illness and interventions, the information gained would be relevant to other cancer patients in similar situations. There are such a large number of chronic physical diseases, including cancer, which have psychological sequelae and demand psychological interventions that it will be impossible to cover all the conditions and their treatments in this study, therefore breast cancer and breast cancer interventions will be the topic under discussion.

### **1.3 PHASES OF BREAST CANCER**

Breast cancer can be classified into three phases or periods according to Anderson (1992) and Mullan (1985) and which will be referred to often in this study. The first phase is the acute or active phase, beginning with the actual diagnosis of the cancer, continuing through the whole treatment procedure which usually includes surgery, chemotherapy, radiation therapy and hormonal therapy (Garcia et al., 2007). The second phase is the extended phase which is

immediately post-treatment and begins when the patient goes into remission or has completed the treatment. This phase can include extended treatment time, for instance, hormonal treatment that can continue for five years after the active treatment or other more chronic interventions when the patient is already in remission. Phase three, the permanent phase, is the remission phase, where there are no signs or symptoms of the breast cancer. Mullan (1995) himself a survivor of cancer, explains the phases of breast cancer through a more psychological and practical lens, describing it as living “with” cancer, living “through” cancer and living “beyond” cancer, but also acknowledges the fact that this process is unique for each cancer patient and the passage from one stage to the next may not always be clearly outlined. Some authors also use the term “re-entry phase survivorship”, which can be defined as the time from treatment completion through 12 to 18 months, while long-term survivors of breast cancer can be defined as being beyond that point (Mulan, 1984; Stanton, 2012). For Park and colleagues (2009) being a cancer survivor represents living after a diagnosis of cancer regardless of whether he or she is still busy with the treatment or how long a person has been alive. Apart from this (more academic) classification, most people experience cancer in two stages, the active or acute phase of treatment and the survivor phase.

#### **1.4 THE DIFFERENCE BETWEEN THE TERM BREAST CANCER PATIENT AND BREAST CANCER SURVIVOR**

Different terminology may be used for the cancer population by both the patient and the oncology team. To differentiate between the terminology of ‘patient’ and ‘survivor’ in this paper, the term cancer patient is seen as an identity which is common and appropriate during active and acute cancer treatment, while cancer survivor is the identity more applicable after treatment in the extended phase (Harwood & Sparks, 2003; Park, Zlateva, & Blank, 2009). Although the researcher uses the term “patient” during the entire study when describing the five participants, it refers more to the status of being actively busy with a psychotherapeutic process than to that of a cancer patient or survivor. In terms of describing the person in the literature, the researcher prefers the terminology “cancer patient” during the active cancer treatment (Harwood & Sparks, 2003; Park et al., 2009) and “cancer survivor” in the post treatment period which is



separated from the timespan encapsulating diagnosis and treatment (Twombly, 2004).

## **1.5 THE CHRONICITY OF BREAST CANCER SURVIVORSHIP**

The progress and advances in the oncology discipline over the last 15 years have led to the reality that cancer is no longer seen as a death sentence since people with cancer are living longer and their cancer may be managed as a chronic illness (Greeff, 2008; McCorkle, Ercolano, Lazenby, 2011; Naus, Ishler, Parrot & Kovacs, 2009). Breast cancer as a chronic illness challenges old school theories that the oncologist's work is completed after treatment and requires of patients and their families to acknowledge their own participation in the management of their illness, emphasising the need for both providers and patients to recognise that cancer care is a long term process, extending beyond the active treatment phase (McCorkie, *et al.*, 2011). In the framework of chronicity, breast cancer survivors often report that they were un-informed and unprepared for the complex rehabilitation process and persistent symptoms of depression or anxiety or other belated side-effects after the end of their treatment (Brem & Kumar, 2011; Burgess, Cornelius, Love, Graham, Richards, & Ramirez, 2005; Dolbeault *et al.*, 2009; Reyes-Gibby *et al.*, 2012).

One of the biggest causes of the chronic status of breast cancer is the continuity and severity of the adverse effects of cytotoxic drugs (chemotherapy) and hormonal therapy, which affects patients both psychologically and biologically (Clark, 2010; Fallowfield & Jenkins, 2015). Chronicity as a status quo "instigates" its own pathology, for example, anticipation anxiety, which is a dominant type of anxiety within the cancer population. Anticipation anxiety has to do with fear and anxiety regarding permanent follow-up appointments with oncologists and regular cancer tests and results to confirm the cancer status and also the fear of recurrence and imminent death (Berger, Mitchell, Jacobson & Pirl, 2015; Lim, Devi, & Ang, 2011). It is a difficult transition for the cancer patient to move from an acute and active cancer patient to "beyond" the treatment stage and if not acknowledged by the oncology team, the cancer survivor, because of a lack of preparation for the re-entry phase, can find herself in a state of limbo without the

necessary skills to learn to live with the chronicity of cancer (Anderson, 1992; Mullan, 1985; Stanton, 2012).

The adjustment to breast cancer survivorship is a complex and lifelong process demanding recognition from the oncology team and the need of certain skills through a psychotherapy process (Naus, Ishler, Parrott, & Kovacs, 2009; Venter, 2014). This chronicity and often permanency of cancer-related side-effects have led to more interest and research regarding the quality of life of the cancer patient and to the balance thereof with improvements in longevity of life (Clark, 2010).

## **1.6 BREAST CANCER AS A TRAUMATIC EVENT**

The very information of being diagnosed with cancer is bound to traumatise the patient and family. It causes a wide range of unanticipated psycho-social problems during the long and tiresome process of cancer treatment. In most cases the diagnosis will rapidly be followed by hospitalisation and surgical intervention, chemotherapy and radiation therapy which are often outside the person's previous experience and can lead to confusion, acute anxiety, fears and even depressive manifestation (Kovac, Petrovic, Nedeljkovic, Kojic & Tomic, 2014). Meier (2010) described a cancer diagnosis as one of the most stressful and traumatic medical diagnoses and that the emotional impact of this diagnosis and the subsequent treatment and chronicity can be extremely overwhelming with effects on the patient's physical, psycho-social and spiritual well-being which could compromise their short and long-term quality of life (Vahdaninia, Omidvari, & Montazeri, 2010). According to statistics at least one in three people with cancer will experience substantial and noteworthy emotional and psychological distress during their illness trajectory (Nekolaichuk et al., 2011).

## **1.7 BREAST CANCER AND PSYCHOLOGICAL DISTRESS**

Recent studies have shown that the prevalence of psychological distress among breast cancer patients is particularly high and that this population is at risk of developing more severe mood disorders such as depression and/or anxiety, which are also the two most common psychiatric disorders in this population (Dolbeault et al., 2009; Lueboonthavatchai, 2007; Navari, Brenner, & Wilson, 2008; Vahdaninia et al., 2010). Depression and anxiety are known to have an influence

on the outcome of cancer treatment and even mortality, as well as on the quality of life of the breast cancer patient, therefore early detection and treatment of these is of value both for the patient and the clinician (Endicott, 1984; Hill et al., 2010; Meier, 2010; Mello, Tan, Armstrong, Schwartz, & Hornik, 2013; Vahdaninia et al., 2010).

### **1.7.1 Breast cancer and psychological distress**

- **Major depression**

Depression in particular has a strong and complex relationship with cancer. Cancer patients experience depression as feelings of sadness and hopelessness, feelings of worthlessness and inappropriate guilt, sleep disturbance and loss of appetite, psychomotor retardation, withdrawal from social activities and heightened expectancy of pain that integrate with the criteria of major depression according to the Diagnostic and Statistical Manual of Mental Disorders-5R (American Psychiatric Association, 2000; Nekolaichuk et al., 2012; Mello et al., 2013; Reyes-Gibby et al., 2012). It is important for the oncology team, especially the psychologist, to understand that all of these symptoms could be related to either the cancer itself or the treatments, such as surgery, chemotherapy, hormone treatment or to depression (Dean, 2008; Gregorio, Jimenez, Rodriguez, & Borda-Mas, 2013; Vahdaninia, 2010). Due to the overlapping of the somatic symptoms the diagnosis of depression can be overseen or difficult to make which often leads to the under diagnosis and treatment of depression, complicating the treatment and outcome of the cancer (Lueboonthavatchai, 2007).

Although there is a high prevalence of depression in cancer patients in general, it was found that women with breast cancer have an even higher risk to develop symptoms of depression because of a premature-menopausal, postmenopausal or oestrogen deficiency state due to their specific cancer treatment. This should make the oncology team more “alert” to their patients and their emotional status (Berger et al., 2015; Gandubert et al., 2009; Navari, Brenner & Wilson, 2008; Reyes-Gibby et al., 2012).

- **Anxiety and anticipation anxiety**



Taking into consideration that a cancer diagnosis confronts a person with his/her own mortality, anxiety is often a psychological reality for the cancer patient (Lim, Devi, & Ang, 2011). Feelings of anxiety after a cancer diagnosis are not necessarily abnormal, for the threat of cancer is to some degree a realistic threat, and must be understood and regarded in this light. However without managing the “normal” anxiety, it may become maladaptive, incapacitating a person’s functioning (Brem & Kumar, 2011; Dolbeault et al., 2009; Lim et al., 2011; Spiegel & Rodrigues, 2008; Stark, Kiely, Smith, Velikova, House, & Selby, 2002). To distinguish between “normal” anxiety and pathological anxiety with regards to the breast cancer patient, the Diagnostic and Statistical Manual of Mental Disorders’ diagnostic classification requires that the following core anxiety symptoms must be present:

- The experience of anxiety must be disproportionate to the level of threat.
- The anxiety symptoms are persistent or deteriorate without treatment and interfere with normal functioning (Stark et al., 2002; van Oers & Schlebusch, 2013).

To give a more general description to a General Anxiety Disorder (GAD): it is characterized by persistent, excessive and unrealistic worry about everyday things and includes worrying beyond a person’s control where they expect the worst even if there is no apparent reason for concern. Anxiety symptoms that a person can experience are: motor tension (trembling, muscle tension and soreness, restlessness), autonomic hyperactivity (shortness of breath, palpitations, sweating, dry mouth, dizziness, nausea or other abdominal distress, flushes, frequent urination and trouble swallowing) and vigilance (feeling on edge, exaggerated startle response, difficulty concentrating and irritability) (American Psychiatric Association, 2000).

Both chemotherapy and radiation therapy are associated with high levels of anxiety and it was found that anxiety is the highest before the first application of chemotherapy and radiation, mediated by age and trait anxiety (Berger et al; 2015; Lim et al., 2011; Lin & Yee, 2011; Lueboonthavatchai, 2007; Sariah & Zainal, 2010; Travado & Reis, 2013; Vahdaninia et al., 2010). Because prolonged anxiety can have immunosuppressive effects on the patient, compromising treatment

outcome and mortality, healthcare professionals should pay greater attention to identify signs of anxiety in patients and design interventions to help alleviate it as early as possible (Shejila et al., 2014; Stark et al., 2002). Anticipation fear and anxiety prior to breast surgery and follow-up examinations and their results are also related to high levels of anxiety (Berger et al., 2015; Travado & Reis, 2013; Van Oers & Schlebusch, 2013; Vahdaninia et al., 2010). Given the anticipated increase in the number of breast cancer survivors over the next few decades, understanding the epidemiology of depression and anxiety and other psychological disturbances and their adverse impacts on quality of life during the survival period, has high clinical and public health significance (Reyes-Gibby et al., 2012).

## **1.8 BREAST CANCER AND SEXUAL FUNCTIONING**

Sex is an important component of most women's lives and the breast cancer survivor is no exception (American Cancer Society, 2013; Kuo, Layden-Wiggins & Dizon, 2008).

### **1.8.1 Definition of sexual distress**

Apart from the possibility of developing a mood disorder, sexual distress and dysfunctions affects a large percentage of women of all ages treated for breast cancer. All current breast cancer treatments can cause changes in the female body that can abruptly affect sexual desire, sexual functioning and changes in intimate relationships (Fobair & Spiegel, 2009; Kaplan, 1992; Sbitti et al., 2011). Sexual dysfunction, during or following cancer therapy is a very complex disorder due to its bio-psycho-social elements and can compound an already stressful life event if not attend to properly (Krychman & Katz, 2011; Speer et al., 2005).

In the context of breast cancer treatment, many women experience sexual problems, yet sexual impairments and challenges have been largely neglected and found to be rarely discussed in oncology due to barriers in sexual health communication between the oncology team and the breast cancer patient. This lack of communication from the side of the oncology team often leads to insufficient information regarding important side-effects of cancer treatment, with the biggest complaint from the breast cancer patient, being that of premature

menopause, and specific sexual dysfunctions, leaving the patient unprepared for the changes (Deeks, Gibson-Helm, Teede, & Vincent, 2011; Derogatis & Kourlesis, 1981; Park, Zlateva, & Blank, 2009). This lack of communication was confirmed in studies showing many participants reporting that they were not properly prepared for sexual changes or equipped to cope with it, leaving the couple feeling negative and unprepared for the unexpected and often long-term sexual side-effects of breast cancer (Gilbert, Perz, & Ussher, 2016; Flynn et al., 2012; Hill et al., 2010). It is important for health care professionals to be conscious of problems related to sexual intimacy and sexual functioning during cancer and cancer treatment and to be prepared to offer information about these aspects and also reflect on their patient's expectations versus the reality (Fallbjork, Rasmussen, Karlsson, & Salander, 2013; Kaplan, 1992). Among the major issues in addressing sexual problems and dysfunctions regarding breast cancer patients, are the lack of recognition that it is a problem and the lack of knowledge about the availability and the effectiveness of interventions for sexual problems (Kuo, Layden Wiggins, & Dizon, 2008). There are few intervention studies addressing sexual adjustment following a cancer diagnosis, with even fewer studies that are entirely focused on addressing sexuality in breast cancer women (Reese, Keefe, Somers & Abernethy, 2010). Krychman and Katz (2011) reported that while sexual problems are an important issue, there are few accepted treatments that have been evaluated for efficacy and safety for these sexual challenges in the breast cancer population and according to these authors, sexuality and intimacy are paramount issues in survivorship care.

## **1.9 PSYCHO-ONCOLOGY**

Historically, the management and treatment of cancer was seated within the framework of the bio-medical model and was predominately focussed on survival and curing, largely overlooking the psychological experience of the cancer patient (Borrel-Carrio, Suchman, & Epstein, 2004; Coleman, Hession & Connolly, 2011; Holland, 2003). Developed from the bio-medical model was the bio-psycho-social model which offered a holistic alternative and provided the platform for psycho-oncology to develop. To comprehend the paradigm of psycho-oncology, a theoretical framework was attained from Engel's humanistic or psychological

model (caring) and Pasteur's bio-medical model (curing), forming the basis and approach of this study (Borrel-Carrio, Suchman, & Epstein, 2004).

During the 14th World Congress of the International Psycho Oncology Society (IPOS) in Brisbane, 2012, it was underlined that cancer services and care should encompass both mental and physical health with the driving principle that there is no health without mental health (Breitbart, Bultz, Dunn, Grassi, & Watson, 2013). In psycho-oncology, the concept of holism was the guiding framework for recent recognition of the significance of comprehensive cancer care. This multidisciplinary field acknowledges and addresses the emotional responses of patients, their families and caretakers as well as the psychological, social and behavioural factors that may influence cancer morbidity and mortality (Haber *et al.*, 1995; Nicolas, 2013; Spiegel, 2012). According to these authors the task for the psycho-oncology experts, now, is to enhance clinical care and practice by nurturing closer connections between psycho-oncologists and health practitioners and to psycho educate them to see the patient and not just the disease.

Being diagnosed with cancer is always shocking for a person and causes a lot of psychosocial distress during their illness and treatment. Due to advances in oncology, cancer treatment has come to be an extremely technical undertaking involving laborious efforts of highly specialised professions, each taking their responsibility for a share of the patient's problem, but often working at a rather impersonal distance from the patient as an individual. This might leave the patient vulnerable and susceptible to psychological distress and in need of specialised services to assist them with decision making and survival in this new and unfamiliar situation (Haber *et al.*, 1995; Kovac *et al.*, 2006). Psycho-oncology classifies the cancer patient as a chronic patient with a continuing threat of recurrence of the disease, long-lasting side-effects due to the treatments and who needs on-going sympathetic contact, even during long intervals between treatments. Integrating the cure and the care as inseparable parts of the medical approach to cancer, both physical and mental health must be meticulously linked (Jones, 2010; Grassi, 2013).

Although the prevalence of distress among cancer patients and the serious adverse impact of it on patient well-being and quality of life have been well

documented, it is as yet not given the warranted attention by both medical physicians and advocates for advancements in cancer clinical practice (Breitbart *et al.*, 2013). Of the 28 million cancer patients worldwide (as well as their family members), only a minority of those in need receive appropriate psychosocial cancer care by trained professionals, resulting in widespread unnecessary and preventable suffering (Breitbart *et al.*, 2013). To illustrate this point, Nekolaichuk and colleagues (2011) said that although many cancer patients access formal psycho-social services, less than 10% are referred for psychosocial evaluation and counselling.

In South Africa the bio-psycho-social perspective is largely accepted as an effective way to treat cancer patients, however the implementation of this approach is still largely absent, both in the private sector and government funded hospitals (Pillay, 2001; Venter, 2014). Some of the reasons for this are the lack of interest in and availability of mental health care in cancer treatment (Manicom, 2010) and the limited studies and literature focussing on the psycho-social factors of cancer (Venter, 2014). It is possible, according to Manicom (2010) that even with limited resources, the oncology teams in South Africa can begin to offer holistic health care to the cancer patient through assisting them (and their families) with psycho-social issues throughout their cancer journey. This can be done by acknowledging and accommodating their psychological responses. Better psychological care can be achieved by more effective employment of mental health and support professionals in multidisciplinary teams and by improved awareness and education of medical professionals in basic patient focused communication. Despite the significance and need for a bio-psycho-social approach when treating cancer patients there is still very little literature available on the psychological interventions in South Africa (Venter, 2010). Research in Africa mainly focuses on bio-medical aspects of cancer, such as physical symptoms and medicine, often overlooking the psychosocial aspects and holistic care of the patient (Selman *et al.*, 2011).

It is the vision of the International Psycho-Oncology Society (IPOS) that all cancer patients and their families throughout the world should receive optimal psycho-social care at all stages of the disease and survivorship, pleading urgency with the



behavioural and social scientists to initiate and develop a psycho-social intervention plan as part of a holistic multidisciplinary quality care for cancer patients (Breitbart et al., 2013). Psycho-oncology is important not only from the standpoint of being humane and improving the quality of the lives of people suffering from a malignant disease, but also from the scientific research aspect because the findings in these areas are still relatively uncommon (Grassi, 2013). Miles (2009) feels very strongly that in this bio-psycho-social era of cancer treatment, it is the task of the oncology team, especially the psychological services, to incorporate and treat the human side of the tumour by making the cancer patient always feel understood and valued as a human being and being treated throughout the whole trajectory of the cancer experience with empathy and dignity.

### **1.9.1 The role of the clinical psychologist in psycho-oncology**

Clinical psychology is the application of psychology to health and community care which involves assessment, improvement and prevention of psychological distress, disability and dysfunctional behaviour (British Psychological Society, 2001; Huey & Britton, 2002). Clinical psychology entered the 21<sup>st</sup> century with an involvement in most medical specialities and across the range of settings in which health care is provided from community to hospital settings. Specific medical specialities, such as oncology, now routinely assume and receive psychological input to patient care (Huey & Britton, 2002). There is a substantial role for the clinical psychologist in health care which will hopefully continue to expand with the continuation of the development and understanding of human behaviour (Huey & Britton, 2002).

Working in the oncology field, the (clinical) psychologist should have a working knowledge of the medical issues the cancer patient will face to be enabled to understand and support the patient emotionally, facilitate decision making during the course of treatment and function as a liaison between the patient and her physician. Familiarity with medical issues makes it simpler for the psychologist to dispel fears, anxieties and myths and to stay focused on the individual's psychological reaction without becoming distracted or overwhelmed by the medical element (Haber et al., 1995).

Rieger and colleagues (1998) suggest a model of service provision where the clinical psychologist is an integral member of the cancer team who routinely sees all cancer patients. The advantage of such a model is a greater facilitation in normalising psychological difficulties in the context of cancer. There is the possibility of preventing or minimising psychological morbidity by early diagnosis and intervention early in the course of cancer and also an opportunity to educate team members regarding psychological issues of cancer. Another model of service provision can also be where the psychologist acts in a liaison capacity on the basis of referrals made by other health professionals and see the cancer patient outside the oncology team. Rieger and colleagues (1998) also feel that a clinical psychologist may contribute to the training and professional development of students and staff operating from various disciplines including psychology, medicine and nursing regarding the psychological elements of cancer and their treatments. This training can include the teaching of communication skills involving empathetic communication and listening and techniques for effective information gathering and emotion management. Sutherland (1958) had already motivated specific education in communication skills for doctors working in the oncology field in the 1950's. Addressing cancer patients' overall needs and sharing complex and often devastating information in an already emotionally charged context and under time constraints, is a daily challenge for the oncology clinician (Bredart, Bouleuc, & Dolbeault, 2005; Sutherland, 1958).

### **1.9.2. Multi-disciplinary teams in oncology**

Because treating breast cancer is considered to be based on a multidimensional concept which comprises biological, psychological, social and spiritual life domains, multidisciplinary teams which integrate these elements, are becoming the model of care for cancer patients worldwide (Carver, 2005; Golden-Kreutz et al., 2005; Jalil, Lamb, Russ, Sevdalis, & Green, 2012; Turner, 2015). Implementing multidimensional treatment of cancer requires specialised professionals and services with interdisciplinary cooperation focusing on patient-centred care through continuous multi-professional collaboration in order to assess and address patient's individual needs (Mathews, West, & Buehler, 2009; Venter, 2014).

The National Health and Medical Research Council (NHMRC) recommend that breast cancer patients should have access to the full range of multidisciplinary treatment options for the successful integration of psycho-social care into routine clinical practice (Nicolas, 2013; Zorbas, Barraclough, Rainbird, Luxford, & Redman, 2003). The principles of multidisciplinary care for cancer include active multidisciplinary engagement, good communication between team members, the availability of psychological services and having access to the full range of therapies. In psycho-oncology, the concept of holism has been the driving force for recent recognition of the importance of comprehensive cancer care, where quality of life is considered an important endpoint in cancer clinical trials (Jalil, Lamb, Russ, Sevdalis, & Green, 2012; Nicolas, 2013; Turner, 2015).

## **1.10 PSYHO-ONCOLOGIC INTERVENTIONS**

### **1.10.1 Psychotherapy: Aims and benefits of cancer-related therapeutic interventions**

The primary aim in cancer intervening psychotherapy is to enhance the quality of life of the cancer patients and survivors through assisting them to achieve optimum functioning within the limits imposed by their cancer (Blake-Mortimer, Gore-Felton, Kimerling, Turner-Cobb, & Spiegel, 1999; Hopko et al., 2011; McQuellon & Danhauer, 2006; Salonen, 2011).

Apart from the evidence that a sufficient percentage of breast cancer patients suffer from psychological hardship, the barriers that keep many patients from benefitting from psychological care services include under-recognition of the need for psychosocial care by the primary oncology team and even when recognized, there is a lack of professional available in many communities to provide psycho-social care to cancer patients (Jacobsen & Jim, 2008, Venter, 2014). Studies confirm that psychological support and psychotherapeutic interventions are clearly unavoidable parts of the complete treatment plan for cancer patients and that psychological interventions have a positive impact on the quality of life of cancer patients (Jacobson & Jim, 2008; McQuellon & Danhauer, 2006; Mens, Helgeson, Lembersky, Baum, & Scheier, 2015; Rehse & Pukrop, 2003). According to Kovac and colleagues (2014) and Nekolaichuk and colleagues (2012) there is still a need for further formal research on the benefits of individual psychotherapy in treating

cancer patients. This study will attempt to demonstrate that individual psychotherapy has an important place in psycho-oncology for it provides an empathetic environment for the exceptional needs of the breast cancer patient.

Apart from providing psychotherapeutic interventions for the breast cancer patient (and family), another responsibility for the psychologist as part of the oncology framework, is to educate the medical staff upfront about what psychological intervention means and the availability and accessibility of psychological services and appropriate referral methods to these services.

#### **1.10.1.1 Cognitive behavioural therapy (CBT)**

Cognitive behavioural therapy (CBT) is defined as psychotherapies that include both cognitive restructuring and behavioural activation. CBT is well researched as a successful therapeutic intervention technique working with breast cancer patients during the trajectory of their cancer journey (Beltman, Voshaar, & Speckens, 2010; Butler, Chapman, Forman & Beck, 2006; Dolbeault et al., 2009; Hale, Treharne, & Kitas, 2007; Montel, 2010; Osborn, Demoncada, & Feuerstein, 2006). A number of studies have reviewed the effectiveness of cognitive behavioural techniques in breast cancer patients, resulting in significant positive outcomes for anxiety, depression, fatigue and general cancer distress (Berger et al., 2015; Carver, 2005; Dolbeault et al., 2009; Golden-Kreutz et al., 2005; Hopko et al., 2008; McQuellon & Danhauer, 2006; Montel, 2010; Osborne et al., 2006; Savard, Simard, Ivers, & Morin, 2005). Components within the structure of CBT such as psycho-education, cognitive restructuring, behavioural activation, problem solving and goal setting, communication strategies and emotional support have all been shown to be effective for a variety of cancer patients because of their ease of administration as well as face validity (Carver, 2005; Golden-Kreutz et al., 2005; Hopko et al., 2008; McQuellon & Danhauer, 2006; Savard et al., 2005). CBT is my therapeutic preference working with cancer patients. I have applied CBT during the psycho-therapeutic sessions with the study participants because it is a dynamic, practical and an applicable method which can be applied short-term and which is easily understood by most people (Hopko et al., 2003; Hopko et al., 2008; Spiegel & Rodrigues, 2008).

Unlike traditional psychotherapy, working in a cancer setting can necessitate consultations in demanding locations such as in a chemotherapy room, or in a hospital room or ward with little privacy for the patient and therapist (Deshields & Nanna, 2010). In spite of the surroundings, it stays the responsibility of the therapist to make the patient feel comfortable and confident enough to participate in a therapeutic conversation. While working predominantly within the framework of individual therapy, I have learned that the cancer patient often asks to bring a family member or her partner with to a session so that “the significant other” can understand the cancer and cancer treatment better from a professional point of view.

### **1.10.2 Sex therapy**

Sex therapy in the oncology framework can be defined as psychotherapy which addresses the breast cancer patient’s psychological and physical sexual problems resulting from breast cancer and breast cancer treatment (Emilee, Ussher, & Perz, 2010; Günzler & Berner, 2012; Speer et al., 2005; Taylor, Harley, Ziegler, Brown, & Velikova, 2011; Ussher, Perz, & Gilbert, 2013). Working with cancer patients sex therapy includes techniques developed by Masters and Johnson such as psycho-education about sexuality and sexual dysfunctions relating to breast cancer and treatments, sensate exercises, cognitive restructuring of inflexible sexual thoughts and pharmacology (Hummel, et al., 2015; Masters & Johnson, 1970; Park et al., 2009). Sex therapy teaches the patients to acknowledge their sexual changes and challenges and to develop new skills to enhance their sex lives and intimate relationships and to accept their “new” sexual status quo (Jun, Kim, Chang, Oh, Kang, & Kang, 2011). Sex therapy can be delivered individually, but can also be couple-focussed, educating both partners about the effects of the cancer on the patient’s sexuality and their sexual relationship (Hummel et al., 2015). Because it is important to maximise sexual wellness during and after cancer treatment, an important aim in sex therapy will be to help the patient to normalize her concerns about her sexuality and sexual functioning. This will prevent sexual pathology from developing and provide a foundation for sex therapy if it is necessary at a later stage (American Cancer Society, 2015; Krychman, & Katz, 2012; Park, et al., 2009).



In spite of confirmation that breast cancer patients have a wide variety of sexual issues and could experience distress, evidence shows that healthcare professionals may not be doing all they can to ensure patients feel able to raise their concerns about sexual problems (Dean, 2008; Derogatis and Kourlesis, 1981; Fobair & Spiegel, 2009; Park et al., 2009). Regarding sex therapy with breast cancer patients, few studies have been done about the availability and the effectiveness of specific psycho-interventions for sexual problems in this population, leaving a gap for further formal studies in this area (Reese, Keefe, Somers, & Abernethy, 2010; Taylor, Harley, Ziegler, Brown, & Velikova, 2011).

## **1.11 AIMS AND RATIONALE OF THIS STUDY**

In the light of the shocking statistics and ever rising number of cancer diagnoses worldwide, especially breast cancer, the time is right for further research in the domain of psycho-oncology and has motivated me as the researcher, due to my interest and involvement in breast cancer, to make this my field of research. The primary aim of this study was to examine and understand the personal experiences and perceptions of breast cancer patients concerning their cancer journey and unique needs for psycho-oncological interventions through their own “voices”. The study further aimed to use this deep and unique knowledge of the breast cancer patients and survivors to fill the gap between clinical knowledge and the practice. It is my hope that this study will make a valuable contribution to research in the field of psycho-oncology in South Africa. This implies increased understanding of the new realities of the chronicity of breast cancer and treatment complications that demand psychotherapeutic interventions in cancer care and initiate new ways of understanding the role of psychology and the psychologist in the medical world of cancer.

## **1.12 METHODOLOGY**

### **1.12.1 Ontology and epistemology**

Constructivism-interpretivism is the chosen epistemological paradigm used in this case study design that will guide the researcher within the framework of postmodernism/idealism (Stake, 2005; Yin, 2003). The constructivism-interpretivism paradigm is a methodological approach that is typical of qualitative

research methods which have the goal to rely as much as possible on the participants' lived experiences. Both constructivists' and interpretivists' approaches believed that the truth is relative and that reality should be interpreted through the meaning that a person gives to his/her lived experiences in order to provide a rich insight into their worlds (Bezuidenhoud, 2014; Creswell, 2007; Ponterotto, 2005; Schwandt, 2000; Schurink & Schurink, 2012;). The constructivist-interpretivist paradigm encourages the researcher to develop a close and prolonged interpersonal relationship with the participants to gain their trust and insights regarding their lived experiences (Ponterotto, 2005).

The researcher's intention with this study, against the background of an interpretative framework, was an attempt to develop a clearer understanding of the lived experiences of the breast cancer patient through exploring her experience of her illness and need for further interventions through her own personal and unique interpretation and voice. In conducting this study, I have adopted two interconnected roles, namely that of an investigator and that of a professional psychologist. In the capacity of an investigator I have explored the breast cancer patients' and survivors' experience of their cancer journey and need for psycho-oncologic interventions through a qualitative research lens. As a professional psychologist I was engaged with the study participants in a psycho-therapeutic relationship providing them psychological support and interventions. The goal of this paradigm which also shares the goal of this study is to rely as much as possible on the participants' lived experiences (Ponterotto, 2005; Schwandt, 2000).

### **1.12.2 Literature review**

The primary use of a literature review in qualitative research is to provide the rationale for a research problem and to assist the researcher in his/her research approach (Creswell, 2007). This includes establishing which ideas to include in the report based on how others have defined and measured these ideas in the past and which questions remain unanswered. Literature studies also help researchers to become familiar with the limitations and challenges of the type of research they intend to execute. The aim is to provide the contextualisation of the arguments of the study and expose the researcher to new ideas and methods by opening

his/her mind regarding the phenomenon studied (Bezuidenhoud, 2014; Henning, van Rensburg, & Smit, 2004; Jaccard & Jacoby, 2010; Maxwell, 2013; Ormston, Spencer, Barnard, & Snape, 2014; Shantall, 1996). Shantall (1996) stated that the more extensive and thorough the literature study is the more accurate and valid the investigation of the phenomenon under research becomes possible.

Before beginning the study, I have completed an extensive literature study on both the biological and psychological aspects of breast cancer and breast cancer treatment. This included aspects like the sensitivity of the oncology medical team regarding the psychological and sexual elements of breast cancer and the availability of psycho-oncologic interventions in this population. I have come to the conclusion that in spite of sufficient statistical proof of the rising numbers of breast cancer worldwide and the devastating and overwhelming biological and psychological side-effects on the patients as well as the occurrence of cancer related psychopathology, there is still little known in the way of the actual voices of the breast cancer patients and survivors regarding their own unique experience of their breast cancer and specific psycho-oncologic needs. I have found very little suggestions in recent literature for specific psychotherapeutic interventions for this population, including sex therapy. To ensure credibility, I have, as the researcher and psychotherapist, made use of thorough research methods, which has included conducting a literature review on breast cancer, both internationally and in South Africa.

### **1.12.3 Case study research design**

#### **1.12.3.1 Qualitative research**

Qualitative research methods are valuable for studying the complexities of the healthcare system and in particular patient experiences (Smith & Firth, 2011). Because this study explicitly aims to understanding the breast cancer patient's unique experiences and specific needs regarding her cancer and relationships with the cancer professionals, the qualitative approach will be appropriate for exploring and describing the complexities of health issues. It will facilitate, through this type of data gathering and analysis methods, a deep understanding of the patient's experience (Smith & Firth, 2011).



The strongest academic rationale for using a qualitative research method is to fill, or add to, a gap in the literature by offering a voice for individuals or a specific population not otherwise heard. Qualitative researchers study phenomena in their natural surroundings and interpret it in terms of the meanings people bring to them (Creswell, 2007; Denzin & Lincoln, 2000; Ormston, Spencer, Barnard, & Snape, 2014). Because of the sensitivity of this study and the needed in-depth understanding of the subject, the justification of this study will be explained against the background of a multiple case study design as part of a mixed method approach.

Because qualitative research is the researcher's chosen paradigm, it is important to give the key features of qualitative research (Creswell & Muller, 2000; Denzin, 1989; Denzin & Lincoln, 2002; Morgan, 2000; Ritchie & Lewis, 2003) which the researcher has followed in this study from the perspective of a postmodernist:

- Qualitative research aims at providing an in-depth understanding of the experiences and perspectives of the phenomena.
- Samples are small and selected according to specific criteria.
- Research is conducted in the participant's normal environment, rather than removing it from personal context for research study.
- Data is collected during a close relationship between the researcher and the research participant.
- Emphasis is placed on rich, thick descriptions of the phenomena being studied.
- Data is detailed and revealing.
- Meaning is given to the data, not by measurement, but by interpretation.

Within this framework, the aim of the study was to provide an in-depth understanding of the experiences and perspectives of the breast cancer patient during and after cancer treatment, using a small and selected sample of five breast cancer patients and survivors. Revealing and detailed data were collected over a period of a year through close relationships between the researcher and the research participants. Information was obtained in the form of written and spoken language and observations. Open-ended data analysis was used to identify and categorise themes which included using the words of the participants.

This offered evidence of patients' different perspectives, patterns of associations, typologies and explanations (Creswell, 2015). The writing of the results has allowed for a thick description of the setting, the participants and the themes in such detail, that readers might be able to feel that they have first-hand experience of the events being described in the study (Denzin, 1989; Ritchie & Lewis, 2003).

Although this study applied both qualitative and quantitative methods, the researcher relied more on qualitative methods, for it suited the aims of this study better. Qualitative methods allow for openness and flexibility in studying complex psychological phenomena in depth through the lived experiences of the people living it (Bezuidenhoud, 2014; Thomas & Magilvy, 2011). Another reason for using qualitative methods in this study is because the researcher believes that it is more beneficial for the phenomenon under study to be explored and understood in depth. It makes the phenomenon more "visible", than the generalising of information to other subjects or settings (Thomas & Magilvy, 2011).

#### **1.12.3.2 Multiple case studies**

Case studies are common research strategies in the field of psychology assisting the researcher to understand complex and sensitive issues and inter-relationships (Hodkinson & Hodkinson, 2001). Case studies, which aim to explore real life experiences and situations in their natural context from multiple angles, are descriptive in nature and provides rich, in-depth and longitudinal information about the phenomena under study (Colman, 2000; Lindegger, 2006; Salminen, Harra, & Lautamo, 2006; Simons, 2009; Yin, 2003 & 2014). Because case studies are grounded in 'lived reality', it has allowed me to obtain rich and in-depth information of the real-life experiences of the breast cancer patient and survivor through lengthy interactions over a time span of one year. I decided to use multiply cases in the study to provide for different stages of cancer treatment and survivorship and to include a wider age range. Multiple cases are considered stronger than single case designs and add more reliability to the study's findings and a deeper understanding of the phenomenon through providing more substantial and powerful analytic benefits (Salminen et al., 2006; Yin, 2003). A case study's unique strength, according to Yin (2014) is its ability to deal with a full variety of evidence – documents, interviews and observations which the researcher has

used in this study. The use of multiple sources of evidence in case study research allow a researcher to address a broader range of historical and behavioural issues, thus the findings and conclusions are likely to be more convincing and accurate (Yin, 2014).

- **Case selection**

The most important criterion in case selection is to ensure that the selection allows for the maximum amount of information to be learned from the cases in question. Each individual case study consists of a “whole” study in which convergent evidence is sought (Salminen et al., 2006). Five breast cancer patients and survivors were selected from both the private sector and a government hospital where the interviews or therapeutic sessions have stretched over one year. The breast cancer patients represented the whole trajectory of breast cancer, from diagnosis to survivorship (up to 2 years), with ages varying from 34 to 62 years. After interviewing and working with the five patients I have felt that a saturation point had been reached and that enough information had been gathered and the phenomenon had been thoroughly disclosed. Saturation is described in the literature as the point in the study where no additional data is found so to develop new elements of the given category, or where the interviewer no longer hears anything new (Lincoln & Guba, 1985; Schurink, 1988). Cosser (2005) feels that with a phenomenon that is complex, the sense of saturation is often intuitive whereas Seideman (1991) feels that criteria for saturation and sufficiency are useful, but practical demands regarding time, money and other resources also play a role.

Inclusion criteria for the study patients included:

- (a) A breast cancer diagnosis – any time from diagnosis through all the stages of the treatment: the patient could also be in remission, but not for longer than 5 years.
- (b) Aged between 30 and 65 years.
- (c) Their understanding and willingness to participate in the study.
- (d) Patients had to live in or around Cape Town.

- (e) Patients must be English or Afrikaans speaking (which are the languages of the therapist).

#### **1.12.4 Data collection**

##### **1.12.4.1 Pilot study**

A pilot study is a preliminary study conducted before implementing the final research design to identify potential problems within the design, especially the research instruments, and to assist the researcher in developing relevant lines of questions (Kanjee, 2006; van der Riet & Durrheim, 2006). A pilot study was done with one breast cancer patient in an attempt to ensure that the questions selected from the literature to be included in the interviews, were clear and adequately covering the field of breast cancer and breast cancer treatment (Venter, 2014; Yin, 2014). It was also implemented to determine practicalities such as the therapeutic environment, the length of the sessions, the susceptibility for psychotherapy and to ask for the patient's input for a more applicable line of inquiry or goals for psycho-therapy.

One of the most crucial changes that was made in this study after conducting the pilot study was to change the (much more) formal and lengthy interview questions to more free range questions, combining the questions with the therapeutic process. This meant that instead of having different interview sessions and therapeutic sessions, I have integrated the questions into the therapeutic process. This was essentially because of time limits (6 to 10 sessions) and because the participants needed to talk more freely about their cancer experiences and therapeutic needs. Another reason was that the type of open-ended questions that were asked almost always triggered a lengthy description of patients' experiences, giving valuable insight into the cancer patient's life, but also served as an emotional catharsis, which was part of the therapeutic process. The information that was accumulated from the pilot study patient was of such significance to the study that the researcher has decided to include her in the number of the case studies.

#### **1.12.4.2 Interviews**

Interviews and observations are essential sources of case study information because most case studies are about human experiences. Qualitative researchers collect data in the form of written or spoken language or in the form of observations that are recorded in language (Durrheim, 2006; Yin, 2003; 2014). Face to face interacting between participant and researcher, as was the case in this study, is regarded a core method of qualitative data collection. This gives the researcher the opportunity to get to know the study participant quite intimately and allows for understanding the depth of the emotions and needs of complicated constructs or experiences (Lewis & McNaughton, 2014; Yeo, Legard, Keegan, Ward, McNaughton, Nicholls, & Lewis, 2014). According to Yeo and colleagues (2014) in-depth interviews are a powerful method for creating description and detailed interpretation of people's social worlds and stress the importance of understanding another person's world through conversation. A qualitative researcher must be skilled in conducting effective interviewing in order to ask relevant questions, be a good listener and interpret the answers fairly and objectively (Schurink, 1988; Yin, 2014).

The researcher in this study entered the research relationship with the study participants as a professional clinical psychologist with years of experience in interviewing and interpreting. Throughout the therapeutic sessions the researcher followed her own line of inquiry, as was reflected by the case study protocol and which was more in the line of fluid conversations than rigid queries. The developed questions that were the guidelines during the psychotherapeutic sessions was open-ended and the primary questions are be described in Appendix A.

#### **1.12.4.3 Quantitative methods**

Qualitative- and quantitative methods, according to Durrheim (2006) complement each other and can be regarded as equal and capable to answer different questions about the same topic. These combined methods can be applied where the study requires measurement of some kind (quantitative method), but also deeper understanding of the nature of an issue (qualitative method) (Ormston, et al., 2014). Although this study has relied more on qualitative research to obtain rich and detailed information, the researcher has used a combination of these two

methods by applying two standardised questionnaires together with the qualitative information methods.

This was done before the start of the therapeutic process in order for the researcher to evaluate the psychopathological status of the study patient during her specific phase of cancer trajectory when intervention starts. It was also to compare what the patient genuinely experienced and was willing to verbalise during an open interview as opposed to what a “scientific” questionnaire reveals about the same topic. The researcher kept in mind that quantitative methods are more rigid and more concerned about objective facts, prediction, generalization and the establishment of universal law-like findings in tightly controlled research environments (Denzin & Lincoln, 2000; Rule & John, 2011; Ormston, *et al.*, 2014; Thomas & Magilvy, 2011). The following instruments were used:

- (a) The Female Sexual Functioning Index (FSFI). Female sexual dysfunction is common among women with breast cancer. The most frequently used instrument to assess sexual functioning in this population is the Female Sexual Function Index which was found a reliable and valid instrument for measuring levels of sexual functioning and cancer-related female sexual dysfunction (Baser, & Carter, 2012). The FSFI is a 19 item inventory and is divided into 6 elements: desire, arousal, lubrication, orgasm, satisfaction and pain (Rosen, Brown, Leiblum, Meston, Shabsigh, 2000; Sheridan, 2005). The FSFI has shown to have good reliability properties with test-related reliability.
- (b) The Hospital Anxiety and Depression Scale (HADS). The HADS has been recognised as a much applied and convenient self-rating instrument for anxiety and depression with both somatic and mental problems and has been validated in cancer populations (Costanini, 1999; Michopoulos *et al.*, 2008; Montel, 2010; Moorey *et al.*, 1991). The HADS consists of 14 items and contains two subscales namely anxiety and depression (Valdaninia, Omidvari & Montazeri, 2010).

#### **1.12.4.4 Strategies for ensuring trustworthiness in qualitative research designs**

Qualitative researchers have developed a unique language that is more suitable to qualitative research and increases credibility, transferability, dependability (consistency) and confirmability (proof) which is the naturalist equivalents for internal validation, external validation, reliability and objectivity that are the concepts used in quantitative research (Creswell, 2007; Guba & Lincoln, 1985; Koro- Ljungberg, 2010; Morrow, 2005). In the scientific context, trustworthiness refers to the replicability of a study's findings (Lewis, Ritchie, Ormston, & Morell, 2014). For the purpose of this study, the proposed criteria, developed by Lincoln and Guba (1985) will be used to address the trustworthiness of the qualitative research. The four criteria agree with the positivist researcher and include credibility, transferability, dependability and confirmability (Guba, 1981; Lincoln & Guba, 1985; Shenton, 2004).

- **Credibility**

Credibility, which refers to the trustworthiness and reliability of the research findings, demonstrates that the subject was accurately identified and described. Credibility can be seen as the alternative to internal validity and is an important criterion for the trustworthiness of a study and can be viewed as an in-depth explanation of the data within their natural setting, population and theoretical framework (Bezuidenhoud, 2014; Shenton, 2004; Tracy, 2010). Detailed description through a literature study and methodology help to communicate the actual context of the problem being studied (Bezuidenhoud, 2014). During this study, I have gained detailed and vivid information from the lived experiences of the five breast cancer patients using their voices to describe their experiences and needs against the background of a complete literature study. I have also used thick, detailed and vivid descriptions of the data with the purpose for credibility and enabling the reader to make decisions about the applicability of the findings to other settings or similar contexts (Denzin, 1989).

- **Dependability /Reliability**



Dependability refers to the stability of data over time and under different conditions with the main goal to minimise the errors and biases in a study. To address this matter, the positivists apply techniques such as thoroughly documenting the procedures followed during the study to demonstrate that if the work were repeated, in the same context, with the same methods and study participants similar results would be attained (Coetzee, 2007; Elo, Kääriäinen, Kanste, Pölkki, Utriainen, & Kyngäs, 2014; Shenton, 2004; Thomas & Magilvy, 2011; Yin, 2014). To enable readers of the research report to develop a thorough understanding of the methods and their effectiveness, the researcher has in this study included the next elements as described by Shenton (2004):

- Describing in detail the research design and its application in terms of what was planned and implemented on a strategic level.
- The operational detail of the data gathering in the field through providing all of the information from the five patients gathered during the therapeutic sessions (that will be displayed in Appendix A).
- Meticulous assessment and analysis of the study data and assessing the effectiveness of the data gathering.
- **Confirmability**

Confirmability relates to the traditional concept of objectivity and means that the data accurately represents the ideas and the experiences of the participants and interpretations of those data are not invented by the inquirer (Elo, Kääriäinen, Kanste, Pölkki, Utriainen, & Kyngäs, 2014; Polit & Beck, 2012; Shenton, 2014). Triangulation, which is a validity procedure that was used in this study, represents the search for integration among multiple and different sources, methods and theories to provide supporting evidence and form categories or themes in a research study (Creswell, 2007; Creswell & Muller, 2000; Lewis et al., 2014). The role of triangulation (Creswell, 2007; Creswell & Muller, 2000; Lewis, *et al.*, 2014) in enhancing confirmability is to reduce the effect of investigator bias and prejudice, as well as detailed methodological description to enable the reader through an “audit trail” to determine the credibility of the data and construct of the study (Shenton, 2004).



- **Transferability**

Transferability can be viewed as the alternative to external validity or generalizability, and indicates that a study's findings must be generalisable beyond the immediate case, regardless of the research method used. In qualitative studies, the aim is more to provide a rich and contextualised understanding of some aspect of lived experience through the intensive study of particular cases, than to generalise (Elo et al., 2014; Merriam, 1998; Polit & Beck, 2010; Yin, 2014). Although most qualitative studies represent a small number of cases, and is not possible to prove that the findings and conclusions are applicable to other situations and populations (Stake, 1994) it is important for the researcher to apply techniques to adhere to the rules of transferability as described by Elo and colleagues (2014). This will include: to communicate the boundaries of the study to the reader, the number of cases that will be included, the principles and criteria used to select participants, the variables, the number of field workers, data collection methods, the number and length of the data collection sessions and the time period over which the data was collected.

In an attempt to meet the above mentioned criteria and to ensure trustworthiness, various strategies such as suggested by Lincoln and Guba (1985), Schurink and Schurink, (2012) and Shenton, (2004) have been employed during this study, included the following:

- As the researcher, I have developed a familiarity with the breast cancer population through working in the industry for many years plus an understanding of the participating establishments (private sector and government hospitals) and went through a process of gaining permission to conduct the study before collecting data (Bezuidenhoud, 2014).
- I have examined previous research studies by conducting a literature study on cancer research both internationally and in South Africa to provide a framework for the findings (Venter, 2014).
- I was engaged with prolonged observation in the field through psycho-therapeutic sessions with the breast cancer patients over a period of a year in weekly and monthly sessions.

- Triangulation of different methods were used where a systematic process of sorting through data to find general themes by eliminating overlapping areas, through the interpretation of only the researcher (Creswell & Muller, 2000).
- I have given an in-depth and detailed methodological description of the phenomenon.
- I have assuring sufficient and suitable data by conducting in-depth interviews with five breast cancer patients and survivors, undergoing adequate interpretation through transcribed interviews (Morrow, 2005).
- I have tried to be as transparent and detailed as possible, which is central to interpretive analysis and represent a thorough explanation of the characteristics, developments and surroundings that represent the experience of the phenomenon being studied (Burr, 2003). Transparency was also presented through detailed descriptions of the selection of participants, composed interview questions, and steps of data analysis. As the researcher, I have used generously quotations from the participants' own words to support interpretations of the data.
- **Ethics**

The fundamental principle of research involving human subjects is to protect the well-being and safety of the research participant (Creswell, 2007; Yin, 2014). Prior to the study, the Ethics Committee of the Psychology Department of UNISA has reviewed and approved the presented proposal to insure the safety and appropriateness of the study (see Appendix D). Because of the two participating state hospital patients, ethical approval was also obtained from the National and Provincial Health Research & Ethics Committees of South Africa (NHRD), who serve as the gatekeeper for monitoring and managing health research for the National Health Research Committee, Provincial Health Research Committees and Research Ethics Committees across South Africa (see Appendix D).

Proper ethical consideration was given to the study through following the ethical requirements described by Creswell, (2007), Koro-Ljungberg, (2010) and Webster and colleagues, (2013).

- The researcher has clearly explained the purpose of the research to the five participants.
- Written and verbal consent from the participants was attained (see Appendix C).
- The study participants understood that their participation will be voluntary and free from any pressure and that they can without any explanation stop their participation from the study.
- Confidentiality and anonymity were guaranteed by the researcher through using pseudonyms and which were explained as such to the participants.
- As the researcher, I believed that the research will be useful and valuable and did not make unreasonable demands on the study participants.
- The commitment of the researcher to accommodate the participant's requests and needs that goes beyond social norms.

#### **1.12.5 Analyses of data**

Although there are no clear prescriptions for analysing qualitative data, the researcher can choose from different possible approaches or methods that are applicable to qualitative research. The interpretive analysis method was used in this study as the main approach including elements such as thematic content analysis, the framework approach and the phenomenological lens (Smith, 2011; Smith & Firth, 2011; Ormston et al, 2014; Yin, 2003). A core ingredient, according to Terre Blance and colleagues (2006) of a good interpretive analysis, which the researcher has comprised, is to stay close to the data and interpret it through empathic understanding. According to these authors, the purpose is not to collect portions of real life, but to place real-life experiences and phenomena into some kind of perspective.

The aim of interpretive analysis is to provide a thick description of the data which can be defined as a thorough explanation or report of the characteristics, processes, and circumstances that represent the phenomenon being studied, which was done by giving the study participants a "voice" to explain their unique experiences and perceptions in their breast cancer environment. The analysis of the data was influenced by the social constructionist data analysis method which focused on interpreting the lived experiences of the participants in the breast

cancer context and allowed the researcher to find significant themes within the text (Ryan & Bernard, 2003; Sprenkle & Piercy, 2005).

To demonstrate the analysis process of this study through the principles that was discussed above has included the next circular process:

- I have collect detailed, insightful face-to-face explanations and descriptions from the five research participants (Smith, *et al.*, 2009).
- I have transcribed the interviews in detail after every session with the study participants.
- I have, through careful reading and re-reading, familiarised myself with the data from the early stages of the interaction with the breast cancer patients, to gain insights of the phenomena being explored, (Creswell, 2007).
- I have then provided a transparent and detailed description of the data through a thorough explanation of the characteristics, developments and surroundings that represent the breast cancer phenomenon (Burr, 2003).
- I have systematically searched and identified patterns within in the data in order to provide an informative description of the studied phenomenon leading to the development of meaningful categories and themes (Basit, 2003; Ormston et al., 2014; Yin, 2003). One of the core elements of analysing within the framework approach is developing a series of interconnected stages which enables the researcher to move back and forth across the data until a clear description emerges which resulting in a refinement of themes that can lead to the development of a conceptual framework (Ayres, Kavanaugh, & Knafel, 2003; Ritchie & Lewis, 2003).
- I have made use of “in vivo” concepts through using the breast cancer patients own language or “voice” and then interpreted the data to make sense of the concepts and themes in terms of the participants’ lives and experiences (Spencer et al., 2014).
- I have tried to remain true to the descriptions of the participants while developing more abstract concepts in analysing the data (Smith & Firth, 2011).

In the light of the purpose and urgency of this study, the researcher has aimed to give a rich and an in- depth clarification of the true experiences and psychological needs of breast cancer patients. I hope that the voices of the study participants will offer new understandings and insights into the psychological world of the breast cancer population to be able to assist them in the best possible way with their psycho-oncologic needs.

### **1.13 OVERVIEW OF THE THESIS**

The thesis includes the following chapters:

The review of the existing literature will be discussed in Chapters II, III, IV and V.

**Chapter II** focused on the statistics and prevalence of breast cancer worldwide and in South Africa and provides arguments for the benefits of studying breast cancer over other cancers. This chapter described the theoretical background of the physiology of breast cancer in terms of the stages and current treatments and the side-effects.

**Chapter III** gave a theoretic overview of the development of psycho-oncology with emphasis on the bio-medical-model and the bio-psycho-social-model with focusing on holism, multi-disciplinary teams and the role of a psychologist in treating the breast cancer patient. This chapter gave a description of the psycho-pathology that is relevant to this study, including major depression, general anxiety disorders, other mood disorders and sexual dysfunctions.

**Chapter IV** described psycho-oncological interventions for breast cancer treatment with special emphasis on individual psycho-therapy with the different therapeutic techniques applicable for the breast cancer population. These techniques include: psycho-education, Cognitive-Behavioural Therapy (CBT), mindfulness-based cognitive therapy and emotional expression. Metastatic- and advanced breast cancer as well as the influence of breast cancer on the family are covered.

**Chapter V** focused on sex therapy as a psycho-therapeutic intervention, covering both biological and psychological elements, describing in detail: The Five A's

comprehensive model of Park and colleagues; Masters and Johnson's model of sensate focusing and flexibility as a model of sex intervention.

**Chapter VI** discusses the research methodology and focuses on the philosophical, paradigm and interpretive frameworks and definitions of the case study research design and assessment measures.

**Chapter VII** contains the discussion of the main themes of each participant's psycho-therapeutic sessions and provides the results of the study.

**Chapter VIII** presents the conclusions, implications for research and practise and limitations.

# CHAPTER II

## LITERATURE OVERVIEW OF CANCER AND BREAST CANCER

### 2.1 CANCER AND BREAST CANCER STATISTICS

#### 2.1.1 Introduction

Breast cancer is the most prevalent cancer for women of all ages throughout the world and ranks as the second highest cause of death. Breast cancer is a major health risk for all women with global statistics showing that the annual occurrence of the disease is escalating (Brem & Kumar, 2011; Howlader, Chen, Ries, Loch, 2014; Reyes-Gibby et al., 2012; Travado & Reis, 2013; Vahdaninia, Omidvari & Montazeri, 2010; Wong & Bloom, 2005). According to the National Cancer Registry network, one in every twenty-six South African women will be diagnosed with breast cancer with approximately 5% younger than 35 years of age. This makes breast cancer the number one malignancy amid women in South Africa (Van Oers & Schlebusch, 2013).

Early and progressed cancer screening and advances in clinical oncology have noticeably led to protracted survival rates in breast cancer patients with percentages as high as 95 when discovered early enough (Cielito et al. 2012; Hummel et al., 2015; Vorobiof, Sitas & Vorobiof, 2001; Weis, Poppelreuter & Bartsch, 2009). According to Fiszer and colleagues (2014) survival after 5 years for early localized breast cancer is now above 96%, while 82% of all women diagnosed with breast cancer can anticipate surviving 10 years.

Survivors of breast cancer are officially the leading group of cancer survivors amongst women in the Western world (Fiszer, Dolbeault, Sultan & Bredart, 2014). For this reason we see the added interest and research on health related quality of life and the critical need to find creative strategies to assist this population in coming to terms with the cancer reality (Greeff, 2008; Hummel et al., 2015).

### **2.1.2 Cancer as a chronic illness**

The progress and advances in the oncology discipline over the last 15 years have led to the reality that cancer is no longer seen as a death sentence since people with cancer are living longer (Greeff, 2008; McCorkle, Ercolano & Lazenby, 2011; Naus, Ishler, Parrot & Kovacs, 2009). Cancer as a chronic illness not only challenges old school theories that an oncologist's work is completed after treatment, but also requires of patients to acknowledge their cancer as a chronic illness with accepting their own participation in the management of their illness (McCorkie et al., 2011). Cancer care, as a chronic illness, occurs on a scale that extends from early detection and diagnosis to the end of life, with treatment, side-effects and survivorship in between (McCorkle et al., 2011).

#### **2.1.2.1 Definition of chronic illness**

Chronic illness or disease can be defined as a long-lasting condition or illness that can be restricted or controlled but not cured and which affects the population worldwide (Arbor, 2011). In the last decades, there have been dramatic shifts in the precedent of diseases from infectious diseases to the present leading causes of mortality dominated by chronic illness. There has been an explosive rise in the incidence of chronic illness in recent years, especially coronary heart disease, diabetes and cancer. These chronic illnesses are viewed as the most common, costly and deadly medical conditions to society and will impose a large liability in the future (Barsky, Friedman & Rosen, 2006; Fortin, Chouinard, Bouhali, Dubois, Gagnon, & Bélanger, 2013; Wright & Kirby, 1999). According to Naus and colleagues (2009) the Census Bureau has projected that over the span of the next 50 years the number of cancer survivors will escalate at a bigger ratio than the occurrence of cancer itself. This estimation proposes the importance of creating a clearly defined model of cancer as a chronic illness in relations to medical treatments and quality of life outcomes.

#### **2.1.2.2 Chronic illness and emotional and sexual outcomes**

Most chronic illnesses like diabetes mellitus, cardiovascular disease and cancer, with their associated treatments, carry a high risk for emotional distress and sexual dysfunctions (Carpenter, Andersen, Fowler, & Maxwell, 2009; Nusbaum, Hamilton & Lenahan, 2003; Richards, Bertolotti, Doss & McCullagh, 2011). A



chronic illness can disturb the quality of life of a person through its antagonistic consequences on, amongst other things, sexual functioning which are often long-term and permanent (Barsky et al., 2006). The emotional impression of an initial cancer diagnosis, its consequent treatment and chronicity can have an extreme and overpowering influence on the patients' quality of life (Nekolaichuk et al., 2012). This will be discussed at length later in this chapter.

### **2.1.3 Different types of cancer with their emotional and sexual side-effects**

A study done by Nekolaichuk and colleagues (2012) have shown that in recent years survival for all types of cancers has grown noticeably from 56% to 62% resulting in patients living longer with prolonged sequelae. According to Katz (2005) and Carpenter and co-workers (2009) the diagnosis of any form of cancer has a distressing impact on the psychological, emotional and sexual welfare of the patient.

The group of cancers (gynaecologic cancers, prostate- and testicular cancers) that are under discussion here are very similar to breast cancer in symptoms, treatments and side-effects, as well as the influence on the patient's quality of life. There are also very clear resemblances between these cancers and breast cancer in terms of the lack of existing research concerning specific guidelines and open communication between patient and treating practitioner that are adequate to address the sexual and emotional demands of this specific cancer population.

#### **2.1.3.1 Gynaecologic cancers**

Endometrial-, ovarian- and cervix cancer, are the three most common gynaecologic cancers. Gynaecologic cancer patients, especially survivors of ovarian cancer have been found to be a high risk for developing depression, anxiety and chronic sexual dysfunction. With the cumulative number of patients attaining long term survival following early stage cervical and endometrial cancer, emanates the need to expand existing understanding of post-treatment sexual adjustment and rehabilitation requirements of this specific population (Juraskova, Butow, Bonner, Robertson, & Sharpe, 2013).



Gynaecologic cancer patients, much like prostate cancer patients, undergo early declines in sexual activity and disturbed responsiveness that can end in a permanent sexual dysfunction (Carpenter et al., 2009). Cervix and endometrial cancers can be treated with radical or total abdominal hysterectomy as part of the surgical treatment plan, which result in the removal or alteration of the sex organs that anatomically influences the cancer patients' sexual functioning (American Cancer Society, 2013; Seungtaek & Eifel, 2009). Because of curative treatments, 85% to 90% of patients with stage 1 cervical cancer will survive their cancer ordeal, needing interventions from the oncology team that can improve their quality of life (Phaendler, Wenzel, Mechanic, & Penner, 2015).

A study done by Phaendler, Wenzel, Mechanic and Penner (2015) shown that cervical cancer patients have worse quality of life scores, not only when compared with the overall population, but also with other gynaecologic cancer patients and survivors. These authors noted that patients with invasive cervical cancer who undergo radical surgery and radiation therapy, scored lower in physical, psychological and sexual domains which ultimately disrupt long-term quality of life. Psycho-social problems affecting quality of life in cervical cancer survivors include mood and stress disorders, body image, and fear of recurrence. In the intense setting among cervical cancer patients treated with high-dose rate brachytherapy, 30% experience acute stress disorder (intrusive memories, vegetative hyper arousal, and avoidance reaction) one week after the end of their treatment (Fossa, & Dahl, 2006). The sexual impact is maybe more prominent amongst cervical cancer survivors because of the younger age (average of 50 years) at the onset of cervical cancer. It is essential to keep finding ways to open the door for survivors to continue to talk about their experience, as is necessary for their sense of continued healing and social support, whether that be with family, friends, or health care providers (Fossa & Dahl, 2006).

### **2.1.3.2 Prostate cancer**

According to McCaughan and colleagues (2013) and the American Cancer Society (2010) prostate cancer accounts for approximately a quarter of all new male cancer diagnoses each year in the UK and North America. In all South Africa population groups, prostate cancer was also the most common male cancer

excluding basal cell carcinoma (Babb, Urban, Kielkowski, & Kellett, 2014). Patients with clinically localized prostate cancer have a positive long-term overall and cancer-specific degree of survival regardless of treatment choice (Koyama, Kang-Hsien, Albertsen, *et al.*, 2013).

Since the median life expectancy after treatment for prostate cancer is 13.8 years, a thorough assessment of long-term functional outcomes (very much the same as in breast cancer) is vital to an understanding of the complete experience of men living with a diagnosis of prostate cancer. According to Resnick and colleagues (2013), literature only reports outcomes in terms of health-related quality of life in patients with prostate cancer that are short-term (1-3 years) or intermediate-term (4-5 years), which might not indicate the long term experience of prostate cancer patients. Prostate cancer patients who undergo a prostatectomy (a surgical operation to remove all or part of the prostate gland) were five times more prone to have urinary incontinence and twice as likely to have erectile dysfunction as the patients who went through radiotherapy. Men in the prostatectomy group were considerably more prone than those in the radiotherapy group to report having erections insufficient for intercourse at two and five years post treatment. Sometimes the erectile dysfunction also goes with urinary incontinence (Resnick *et al.*, 2013).

According to Chung and Brock (2013) the challenges for prostate cancer survivors comprise the probability of prostate cancer recurrence and management of physical, cognitive, sexual, and socioeconomic quality of life concerns. Sexual dysfunction is one of the most common, distressing and persistent adverse effects of prostate cancer treatment, and has a profound effect on the quality of life for the patient and his partner (Cormie, Newton, Taaffe, Spry, & Galvao, 2013). Many prostate cancer patients report a loss of masculinity which can sometimes be caused by effects of androgen deprivation therapy (ADT). Loss of masculinity in prostate cancer patients is a multi-layered concept that may be influenced by decreased perceptions in their self-confidence, competitiveness, control, mental state, vulnerability to stress and the ability to provide for the family. These factors are likely to increase anxiety and depression and must be considered as treatment

targets whether through antidepressant medication and/or psychotherapy (Sharpley, Bitsika & Denham, 2014).

Sexual function remains an imperative issue in men who often continue to be interested and active in sex after prostate cancer treatment. A recent study done by Cormie and colleagues (2013) implied that current health-care provisions are inadequate to address the demand for the management of sexual dysfunction, with approximately half of prostate cancer survivors reporting unmet sexual health-care needs. The various post-prostate cancer treatment-related sexual dysfunctions are:

- a) Penile deformities and erectile dysfunction.
- b) Lack of sexual desire and mental health (depression and anxiety).
- c) Ejaculatory and orgasmic dysfunctions.
- d) Changes in partner response (Chung & Brock, 2013).

Yet, despite literature concerning prostate cancer related sexual dysfunctions, there are no existing recommendations or guidelines concerning optimal rehabilitation or treatment protocol for the above said dysfunctions. Medical, surgical and pharmacological interventions are effective in erectile function recovery and/or preservation, but psychological and sexual counselling are as important in sexual rehabilitation, relationships and dynamics (Cormie et al., 2013).

Resnick and colleagues (2013) concluded that prostate cancer patients undergoing a prostatectomy or radiotherapy had declines in all functional outcomes, including emotional and sexual, throughout early, intermediate, and long-term follow-up. Even in the light of possible emotional and sexual dysfunctions and changes in the relationship, it is documented that men are low consumers of cancer information and support services (McCaughan, Prue, McSorley, Northouse, Schafenacker, & Parahoo, 2013; Weber et al., 2004). Men also tend not to recognize or acknowledge illness or openly discuss concerns.

### **2.1.3.3. Testicular cancer**

The most frequent cancer in men from 15 to 44 years is testicular cancer which mainly affects the white Caucasian population. This cancer is the most common malignancy among young adult men ( Le Cornet et al., 2014; Znaor, 2014). The needs of this cancer population may vary from enduring the impacts of the diagnosis, treatment and its side effects and the patient's relative youth. Testicular cancer can create practical encounters including difficulty in getting life insurance and psychological concerns including fear of cancer recurrence and generally unexpected phenomena by younger men associated with substantial personal and professional implications (Smith et al., 2013).

The long term physical effects of testicular cancer treatments may impact potential infertility, changed neurological and respiratory function and increase the risk of secondary malignancy and cardiovascular disorder (Smith et al., 2013). In a recent study, these authors confirmed that the psychological requirements of the testicular cancer patients often go unmet. Younger age and the chronicity of the illness were associated with a higher frequency of unmet needs. Sixty-seven percent of the testicular cancer survivors acknowledged a need for help with relationship and sexual issues, but only a small percentage will seek help from health professionals. Unfortunately, unmet psychological needs lead to lessened mental-health related quality of life. Testicular cancer survivors, similar to many other (young) men, are concerned about the stigma/shame connected to seeking professional (especially psychological) help (Smith et al., 2013).

### **2.1.4 Summary**

It is evident that a chronic illness, with the trauma of the diagnosis and life-long liability and adjustments, can alter the quality of the lives of these patients. It also impacts the quality of the lives of their families and partners in a permanent manner. Cancer, especially breast cancer with its large population of survivors, is now formally acknowledged as a chronic illness. With the new status of chronic illness, more complications arise in terms of life-long side-effects of medications and treatments and the condition itself. Knowledge is needed, not only from the biological side (the medical team), but especially from the psychological side. It is needed to assist these patients in developing new approaches and skills to adapt

to and manage these chronic conditions, together with their families, for a better quality of life. Because of the many shared characteristics of different chronic illnesses, especially cancer, and the general influences of treatments on the human body and psyche, it is imperative to understand the long term psychological consequences on the quality of life of chronically ill patients. Because of the similarity of these conditions, information, newly developed theories and models from different chronic disorders can be applied throughout the spectrum of chronic illness disease.

## **2.2. THE BIOLOGY OF BREAST CANCER**

According to Haber and colleagues (1995) understanding the specific cancer terminology and procedures is crucial for the psychologist working with cancer patients. Having a working knowledge of the medical experience of this patient population in terms of diagnosis and prognosis, treatment plan, side effects, level of pain and possible level of functioning or dysfunctionality during the trajectory of her illness and treatment, the psychologist will be able to understand and psychologically support the patient. In understanding the medical side of breast cancer, the psychologist will be skilled in facilitating decision making during the course of treatment. This can be done when the patient feels overwhelmed and the psychologist can act as a liaison between the patient and her physician.

Fallowfield and Jenkins (2015) reported that breast cancer is no longer a simple disease to explain to patients. Because of booklets, DVD's, leaflets and technology (e.g. the internet), patients have access to, and improved knowledge of the medical world of cancer and will ask appropriated questions that must be met and explained with proper knowledge from the cancer team, including the psychologist (Fallowfield & Jenkins, 2015). Patients also familiarise themselves with, and use specific terminology (as used by their oncologists), in the psychotherapeutic sessions, and therefore the psychologist must have the proper knowledge of the so-called "cancer language". According to Fallowfield & Jenkins (2015) breast cancer patients not only suffer emotional mayhem, but they also enter an abnormal and unexpected new world of unfamiliar language and concepts. To ensure that the patient can provide educated and informed consent to treatment plans, it asked for excellent communication skills from the healthcare

professionals involved with breast cancer treatment. For this reason it is important for the psychologist to acquaint himself/herself with the associated cancer care knowledge.

To be able to do this, the psychologist must understand the basic terminology of cancer and cancer treatments. Not to be overly medically complex, this study will give descriptions and definitions of cancer, stages of cancer, different diagnosis and treatment modalities and biological side-effects, which will explain a very complex and difficult illness for the psychologist to understand and apply in the psychological framework.

### **2.2.1 Cancer terminology and definitions**

The term breast cancer indicates a malignant tumour that develops from cells in the breast (Amin, Purdy, Mattingly, Kong, & Termuhlen, 2013). Breast cancer is a heterogeneous disease in which abnormal cells grow in an uncontrolled way (Li, Uribe & Daling, 2005). A malignant tumour is a cancerous growth that begins in the tissues of the breast and is caused by a genetic abnormality as described by the breast cancer organization (<http://www.breastcancer.org/>). If left unchecked the malignant cells can eventually spread beyond the original tumour to other parts of the body (Amin, et al., 2013).

The most common types of breast cancer are:

- **Ductal Carcinoma in situ (DCIS):** starts in the cells which line the breast's ducts / tubes beneath the nipple and areola. Between 85% and 90% of all breast cancers are ductal. Ductal carcinoma in situ it is well contained and not invasive and can be treated successfully through a lumpectomy. If the tumour margins are clear of cancer, follow-up treatment may include radiation (Solin et al., 2013).
- **Lobular Carcinoma in situ (LCIS):** starts in the lobes or glands which produce milk in the breast. The lobes are located deeper inside the breast, under the ducts and account for around 8% of all breast cancers. LCIS indicates the cancer is restricted within the lobes and has not spread to other areas in the breast. This cancer can be removed during a

lumpectomy and if the tumour margins are clear of cancer, follow-up treatment could include radiation (Solin et al., 2013).

- **Invasive Breast Cancer:** When breast cancer is invasive, it started in the breast glands or ducts but grows or spread into the breast tissue or nearby lymph nodes and beyond. In the case of invasive breast cancer a mastectomy and chemotherapy may be needed (Solin et al., 2013).
- **Inflammatory Breast Cancer (IBC):** This cancer is less common and considered an aggressive cancer because it grows quickly, is more likely to have spread at the time it is diagnosed and is more likely to recur after treatment than most other types of breast cancer. Treatment guidelines for inflammatory breast cancer include chemotherapy before surgery to help shrink the cancer and reduce the swelling and help the inflamed skin return to normal. Most women with IBC usually have a mastectomy after the chemotherapy, followed by radiation therapy. When diagnosed early, inflammatory breast cancer can be a manageable disease with survival rates on the increase. This clinical form of breast cancers typifies 1% to 6% of all breast cancers with a prognosis which is the worst of all the types of breast cancer because of an almost constant metastatic evolution (Chevallier, Asselain, Kunlin, Veyret, Bastit, & Graic, 1987; Gonzalez-Angulo et al., 2007).
- **Locally Advanced Breast Cancer:** This cancer characterizes a heterogeneous class of tumour and represents disease with a rapid growth rate particularly for inflammatory breast cancer which is a subcategory of locally advanced breast cancer (Buchholz, 2009).
- **Metastatic breast cancer (MBC)** is a heterogeneous cancer with a diversity of different clinical scenarios, fluctuating from single metastatic lesions to multiple organ involvement. Metastasis of breast cancer occurs primarily through the lymphatic system, and the extent of lymph node involvement is a key prognostic factor for the disease (Skobe et al., 2001).



Overall, survival of patients with MBC is gradually improving. The risk of death is decreasing by 1%–2% each year (Pagani et al., 2010).

- **Paget's disease (PD):** The least common type of breast cancer is Paget's disease of the breast. It is also known as Paget disease of the nipple and mammary Paget disease. It is a rare disorder of the nipple-areola complex that is often associated with an underlying in situ or invasive carcinoma (Blanchard, Sarr & Farley, 2001; Kollmorgen, Varanasi, Edge, & Carson III, 1998). This form of cancer is usually treated with a mastectomy because the cancer has by then invaded the nipple, areola and the milk ducts (Kawase et al., 2005, Kollmorgen, Varanasi, Edge & Carson, 1989; Sakorafas, Blanchard, Sarr & Farley, 2001).
- **Recurrent breast cancer:** Around 40% of all patients with breast cancer suffer a recurrence; most of them die from it. The risk of recurrence is highest in the first 2–3 years and then decreases continuously, although it never reaches zero (Freund & Reimer, 2010).

## **2.2.2 Stages and grading of breast cancer for diagnostic and prognostic reasons**

The management of breast cancer relies on the availability of strong clinical and pathological prognostic and predictive factors to direct patient decision making and the choice of treatment options (Rakha et al., 2010). A range of clinical and pathological factors are routinely used to classify patients with breast cancer in order to assess prognosis and establish the appropriate therapy. These include patient age, axillary lymph node status, tumour size, histological grading and hormone receptor status (Schnitt, 2010).

### **2.2.2.1 Grading system**

Grading identifies a measure of the probable degree of a tumour and where the most malignant growths having spread to and can be carried out on a surgical specimen or through histology (blood). The grade of the cancer is representative of the aggressive potential of the tumour. Grading also indicates the chance of metastases being present in regional lymph nodes and distant organs (Bloom &

Richards, 1957; Rakha et al., 2010). Determining the grade is imperative for the clinicians to guide them in planning the treatment.

There are different scoring systems available for determining the grade of the breast cancer. One of these systems is the Nottingham Grading System (NGS) which is recommended by various international professional bodies and provides a simple, inexpensive and regularly applicable indication of the basic biological characteristics and clinical behaviour of tumours (Rakha et al., 2010). The grade of a breast cancer is representative of the aggressive potential of the tumour, the lower the grade, the less aggressive the tumour.

**Grade 1 (G1):** A low grade. If the cells of the tumour and the organization of the tumour's tissue are close to those of normal cells and tissue, the tumour is called well differentiated and slow growing and is less likely to spread (divide).

**Grade 2 (G2):** Is moderately differentiated or undifferentiated and is an intermediate grade and have qualities between grade 1 and grade 3.

**Grade 3 (G3):** Is a high grade, poorly differentiated, rapid growing and more likely to spread (Bloom & Richardson, 1959; Ivshina et al., 2006).

Bloom and Richardson (1957) accentuate the importance that grading is indeed only a guide and should not be regarded as a method of predicting outcome with any degree of mathematical exactness. Patients should talk to their physicians regarding their tumour grading and the influence on their treatment and prognosis (Ivshina et al., 2006).

#### **2.2.2.2 Stages of breast cancer**

Tumour grade is not the same as the stage of cancer. Cancer stage refers to the size and or the extent of the original (primary) tumour and whether or not cancer cells have spread in the body. How the physician describes a cancer's growth or spread is called a stage. Cancer staging is based solely on the anatomic extent of cancer and remains primarily anatomic (Edge & Compton, 2010). The cancer's stage is one of the most important factors in determining prognosis and treatment options. Staging provides a common language for doctors to effectively

communicate about a patient's cancer and collaborate on the best courses of treatment (Rakha et al., 2010, American Cancer Society, 2014).

How does Staging Work?

Physicians use data they collect from various tests and use it to identify staging in breast cancer.

These tests can include:

- **Physical examinations;** may determine the location and size of the tumour(s) and offer additional information on whether the cancer has spread to the lymph nodes and/or to other organs.
- **Imaging tests;** such as x-rays (mammography), CT- and MRI scans, which can show the location of the cancer, the size of the tumour, and whether the cancer has spread.
- **Laboratory tests;** that provide information on blood, urine and other fluids and tissues removed from the body and studying under a microscope.
- **Pathology reports;** that provide information about the size of the tumour, the growth into other tissues and organs, the type of cancer cells and the grade of tumour. Pathology reports often confirm the diagnosis of cancer, as well as the stage.
- **Surgical reports;** tissue samples removed during surgery can determine the size and form of a tumour and provide insights about lymph node and organ metastases (American Cancer Society, 2014, Bloom & Richardson, 1957; Edge, & Compton, 2010; Rakha et al., 2010; Singletary & Connolly, 2006).

The pathologic stages of breast cancer are based on four characteristics as described by Howlader and colleagues (2014).

- The size of the tumour.
- If the cancer is invasive or non-invasive.
- The presence of any lymph nodes metastases.
- The presence of distant organ metastases

The breast cancer organization defines staging as a way of describing where the cancer is located, how much the cancer has grown and if or where it has spread.

**STAGE 0** - is non-invasive cancers, such as ductal carcinoma in situ. In stage 0 there is no evidence of cancer cells or non-cancerous abnormal cells breaking out of the segment of the breast in which they started, or invading adjoining normal tissue.

**STAGE I** - defines invasive breast cancer where the cancer cells are breaking through and invading normal surrounding breast tissue. Stage I is divided into subcategories known as IA and IB.

Stage IA defines invasive breast cancer in which:

- The tumour measures up to 2 centimetres.
- The cancer has not spread outside the breast and no lymph nodes are involved.

Stage IB defines invasive breast cancer in which:

- There is no tumour in the breast but small groups of cancer cells, not larger than 2 millimetres are found in the lymph nodes.
- There is a tumour in the breast that is not larger than 2 centimetres and small groups of cancer cells, not larger than 2 millimetres in the lymph nodes.

**STAGE II** - Stage II is divided into subcategories IIA and IIB:

Stage IIA defines invasive breast cancer in which:

- No tumour is located in the breast but is found in 1 to 3 axillary lymph nodes under the arm (but not larger than 2 millimetres) or the lymph nodes near the breast bone, OR
- The tumour in the breast measures 2 centimetres or smaller and has spread to the axillary lymph nodes OR
- The tumour is larger than 2 centimetres but not larger than 5 centimetres and has not spread to the axillary lymph nodes.

Stage IIB defines invasive breast cancer in which:

- The tumour is larger than 2 centimetres but not larger than 5 centimetres; or small groups of breast cancer cells, (not larger than 2 millimetres) are found in the lymph nodes OR
- The tumour is larger than 2 centimetres but not larger than 5 centimetres; cancer has spread to 1 to 3 axillary lymph nodes or to lymph nodes near the breastbone OR
- The tumour is larger than 5 centimetres but has not spread to the axillary lymph nodes.

**STAGE III** - Stage III is divided into subcategories known as IIIA, IIIB and IIIC.

Stage IIIA defines invasive breast cancer in which either:

- No tumour is found in the breast or the tumour may be any size; but cancer is found in 4 – 9 axillary lymph nodes or in the lymph nodes near the breastbone OR
- The tumour is larger than 5 centimetres; small groups of breast cancer cells (not larger than 2 millimetres) are found in the lymph nodes OR
- The tumour is larger than 5 centimetres; cancer has spread to 1 – 3 axillary lymph nodes or to the lymph nodes near the breastbone.

Stage IIIB defines invasive breast cancer in which:

- The tumour can be any size and has spread to the chest wall and/or skin of the breast and caused swelling or an ulcer AND
- The tumour may have spread to up to 9 axillary lymph nodes OR
- The tumour may have spread to lymph nodes near the breast bone.

Inflammatory breast cancer is considered at least stage IIIB. Typical characteristics are:

- Reddening of a large portion of the breast skin.
- The breast will feel warm and may be swollen.
- Cancer cells have increased or spread to the lymph nodes and may be found in the skin.

Stage IIIC defines invasive breast cancer in which:

- There is no sign of cancer in the breast, or, if there is a tumour, it can be of any size and may have extended to the chest wall and /or the skin of the breast AND
- The cancer has spread to 10 or more axillary lymph nodes OR
- The cancer has spread to lymph nodes above or below the collarbone or the breastbone.

## **STAGE IV**

This stage defines invasive breast cancer that has spread beyond the breast and nearby lymph nodes to other organs of the body, such as the lungs, distant lymph nodes, skin, bones, liver or brain. Associated words with stage IV are “advanced” and “metastatic”. All of the information about the Stages of breast cancer was retracted from Bloom and Richardson (1957), Chevallier and co-workers (1987), Haffty (2009), Howlader and co-workers, Ries and colleagues (2014) and the breast cancer organization (<http://www.breastcancer.org/>).

The Tumour-Node-Metastasis (TNM) system is another classification that offers more details about the appearance and “actions” of the cancer and is the most commonly used tool for doctors to describe the stage of the cancer. This system was developed in an attempt to classify cancer based on the major morphological characteristics of cancerous tumours which can influence disease prognosis (Haber et al., 1995; Haffty, 2009; Howlader et al., 2014, Singletary & Connolly, 2006). The TNM system is based on three features and the doctors or oncologist use the results from diagnostic tests and scans to answer the following questions:

- **Tumour (T):** How large is the primary or the original tumour? And where is the tumour located? The T classification is about the size of the primary or original tumour and the extent of the tumour growth within the breast;
- **Node (N):** Has the tumour spread to the lymph nodes? And if so, where are they located and how many are there? The N classification has to do with the presence and extent of regional lymph node involvement;

- **Metastasis (M):** Has the cancer metastasized to other parts of the body? If so, where and how much? (Haber et al., 1995, Haffty, 2009; Howlader et al., 2014; Singletary & Connolly, 2006).

There are 3 other TNM descriptors that oncologists use when applicable, which are m (multiple foci of invasive carcinoma), r (recurrent) and y (post treatment).

### **Tumour (T):**

Using the TNM system the “T” plus a letter or number (0-4) is used to describe the size and location of the primary tumour. Some stages are separated into even smaller groups that help describe the tumour in more detail.

The clinical measurement used for classifying the primary tumour (T) will depend on the specific case, e.g. physical examination or imaging such as mammography or ultrasound. The size of the primary tumour is measured before any tissue is removed for special studies.

**TX:** Implies that the primary tumour cannot be evaluated.

**T0:** Implies that there is no evidence of the primary tumour in the breast.

**Tis:** Refers to carcinoma in situ, which means the tumour has not begun to grow into healthy breast tissue and is restricted within the ducts or lobules of the breast tissue. There are three types of breast carcinoma in situ:

**Tis (DCIS):** Ductal Carcinoma in situ is a non-invasive cancer, where the cancer cells have been found in the breast ducts and have not spread past the layer of tissue where they began.

**Tis (LCIS):** Lobular carcinoma in situ defines abnormal cells found in the lobules or glands of the breast, although it is not cancer yet, it enlarges the risk of developing invasive breast cancer.

**Tis (Paget’s):** Paget’s disease of the nipple with no tumour is a rare form of early, non-invasive cancer that is only in the skin cells of the nipple.

T1, T2, T3, and T4: These numbers are based on the size of the tumour, the higher the T number and the larger the tumour and/or the more it may have grown into the breast tissue.

**T1:** The invasive part of the tumour in the breast is 20 millimetres (mm) or smaller.

**T2:** The invasive part of the tumour in the breast is larger than 20 mm but not larger than 50 mm.

**T3:** The invasive part of the tumour is larger than 50mm.

**T4:** The tumour falls into one of the following groups:

- **T4a:** The tumour has grown into the chest wall.
- **T4b:** The tumour has grown into the skin.
- **T4c:** The cancer has grown into the chest wall and the skin.
- **T4d:** Represent inflammatory breast cancer.

**Lymph Nodes (N):** The lymph nodes that are found under the arm, above and below the collarbone and under the breastbone are called regional lymph nodes. Lymph nodes in other parts of the body are called distant lymph nodes. The N category defines if the cancer has reached nearby lymph nodes:

**NX:** Implies that regional lymph nodes can't be measured or found.

**N0:** No regional lymph node metastasis was found in the lymph nodes.

**N1:** The cancer has spread to between 1 and 3 lymph nodes under the arm and is at least 2 mm in size. It is also called macro metastasis.

**N2:** Cancer within the lymph nodes falls into one of the following categories:

- **N2a:** The cancer has spread to 4 to 9 axillary lymph nodes.
- **N2b:** When the cancer has spread to internal mammary lymph nodes (lymph nodes under the sternum or breastbone) without spread to the axillary nodes.

**N3:** The cancer falls within one of the following groups:



- **N3a:** The cancer has spread to 10 or more lymph nodes under the arm or clavicle or collarbone.
- **N3b:** When the cancer has spread to the internal mammary nodes and the axillary nodes.
- **N3c:** Is when the cancer has spread to the lymph nodes located above the clavicle, called the supraclavicular lymph nodes.

If there is cancer in the lymph nodes, the oncologist can, by knowing how many lymph nodes are involved and where they are located, plan the most effective treatment plan. If cancer is found in the lymph nodes, treatment other than surgery, such as chemotherapy, radiation therapy and hormonal therapy can be used. If the doctor assesses the lymph nodes before surgery, based on other tests and/or a physical examination, a letter “c” for “clinical” staging is placed in front of the “N.” If the lymph nodes are evaluated after surgery, which is a more accurate assessment, a letter “p” for “pathologic” staging is placed in front of the “N.”

### **Metastasis (M):**

The M in the TNM system specifies whether the cancer has spread to other parts of the body. It is also called distant metastasis.

- **MX:** indicates that distant metastasis cannot be measured or found.
- **M0:** indicates there is no distant metastasis.
- **M1:** There is evidence of metastasis to another part of the body, indicating that there are cancer cells growing in other organs.

In addition, a stage may be determined after therapy for the breast cancer patient who receive systemic (chemotherapy or hormone) therapy, or radiation therapy before surgery, or when no surgery is performed. This is termed neo adjuvant therapy staging or post therapy staging (yTNM) (Edge & Compton, 2010).

The TNM staging procedure includes four classifications: clinical, pathologic, recurrence and autopsy.

- **Clinical classification (cTNM):** It is based only on evidence gathered before initial treatment of the primary tumour and is used to make local

treatment suggestions. It can be through physical examination, imaging studies (including mammography and ultrasound) and pathologic examination of the breast or other tissues obtained from a biopsy as appropriate to establish the diagnosis of breast cancer.

- **Pathologic classification (pTNM):** It includes the results of clinical staging with evidence obtained from surgery and from detailed pathologic examination of the primary tumour, lymph nodes and distant metastases (if present). It is used to assess prognosis and to make recommendations for adjuvant treatment.
- **Recurrent classification (rTNM):** This classification is used when the cancer has come back after treatment and can be either local or distant or both. If the cancer has re-occurred, there will be another round of tests to learn about the extent of the recurrence. These tests and scans are often similar to those done at the time of the original diagnosis.
- **Autopsy classification (aTNM):** is used for cancers discovered after the death of a patient, when the cancer was not detected before death. All of the above information was from work done by Bloom and Richardson (1957); Carter, Allen and Henson (2006); Howlader and colleagues (2014) and Singletary (2006).

Once the pathologist knows the TNM characteristics, it will be used to assign a stage to the cancer and then be used by the physician and the rest of the oncology team to help guide the treatment options for the patient.

### **2.2.3 Procedures in Making the Diagnoses of Breast Cancer**

There are different procedures in making the diagnosis of breast cancer performed by different specialties which include the following:

#### **2.2.3.1 Mammogram**

A mammogram is a specialised medical imaging that uses low dose X-rays of the soft tissue in the breast that is taken with a mechanism that compresses and flattens the breast. A mammogram can identify small lesions before they can be detected by touch and distinguish whether a lump in the breast is a gland, a harmless cyst or a tumour (Haber et al., 1995). Mammography can portray

calcifications due to malignancy/a tumour, including ductal carcinoma in situ (DCIS) (Berg, et al., 2008).

Mammography is a top-quality method and the gold standard for breast imaging and cancer detection (Jalalian, Mashohor, Mahmud, Saripan, Ramli, & Karasfi, 2013) and reduces mortality from breast cancer (Lee, et al., 2010). However, due to some limitations of this modality such as low sensitivity especially in dense breasts and women with increased risk for breast cancer, other screening modalities like ultrasound and magnetic resonance imaging (MRI) are often propose to achieve additional information to enable a more accurate diagnosis of breast cancer (Mashohor, 2013; Saslow et al., 2007; Lee et al., 2010).

#### **2.2.3.2 Sonography**

Ultrasound imaging is one of the most frequently used diagnosis tools to detect and classify abnormalities of the breast (Cheng, Shan, Ju, Guo, & Zhang, 2010). Sonography is a useful adjunct after mammography for the detection of non-palpable (not clear) breast cancer, particularly in the dense breast (Leconte et al., 2003) and using both sonography and mammography increases the sensitivity for the detection of cancer from 83% to 91%.

#### **2.2.3.3 Magnetic resonance imaging (MRI)**

Magnetic resonance imaging uses magnetic fields to produce detailed cross-sectional images of tissue structures, postulating very good soft tissue contrast and has higher sensitivity that the mammogram to find smaller tumours (Saslow et al., 2007). The MRI is used widely both for screening women who are at increased risk of breast cancer and for treatment selection. Prospective studies (Morrow, Waters, & Morris, 2011) confirm that MRI screening of women with known or suspected genetic mutation results in a higher sensitivity for cancer detection than does mammography on its own.

#### **2.2.3.4 Biopsy**

A biopsy is the removal of cells or tissues for examination by a pathologist. The most common types of biopsies include:

- (1) Incisional biopsy, in which only a sample of tissue is removed;

- (2) Excisional biopsy, in which an entire lump or suspicious area is removed; and
- (3) Needle biopsy, in which a sample of tissue or fluid is removed with a needle. When a wide needle is used, the procedure is called a core biopsy. When a thin needle is used, the procedure is called a fine-needle aspiration biopsy (Haber et al., 1995; NCI Dictionary of Cancer Terms).

#### **2.2.4 Biological breast cancer treatments**

There have been some exceptional advances the last three decades in breast cancer treatments that offer women better prospects of cure or longer good-quality survival (Fallowfield & Jenkins, 2014). Biological breast cancer treatments can be divided in two categories namely, local treatments and systemic treatments.

##### **2.2.4.1 Local Treatments**

Local therapy means treating the breast tissue itself and can be achieved by either a lumpectomy or mastectomy. Surgical removal of the tumour remains the keystone of management with early breast cancer and traditionally it would have meant a mastectomy (removal of the whole breast) with or without axillary dissection (Veronesi et al., 2002). Currently with all the treatment advancements, the first line of treatment now is wide local excision (lumpectomy) followed by radiation therapy to the intact breast (Haffty, 2009).

###### **2.2.4.1.1 Lumpectomy**

A lumpectomy falls in the category of breast conserving therapy which means saving the normal breast tissue while removing only the cancer. A lumpectomy per definition implies the removal of the lump in the breast and a sample of lymph nodes under the arm (Haber et al., 1995).

The principal advantage of the lumpectomy is that the result is less disfiguring than that of a mastectomy. In addition to a lumpectomy, radiation is almost always given to increase the effectiveness of surgery (Haber et al., 1995; Meric, 2003). According to van Dongen and colleagues (2000) and Meric and co-workers (2003) breast conserving therapy plus radiation therapy has been shown to be as effective as a mastectomy for most patients with stages I and II breast cancer.

#### 2.2.4.1.2 Mastectomy

As stated above, the mastectomy (removal of the whole breast) was the treatment of choice for breast cancer of any size or type, regardless of the patient's age (Veronesi et al., 2002), and although breast conservation has become more widely used in early breast cancer, mastectomy still remains the keystone of treatment (Meric et al., 2003). There are two types of a mastectomy: a) Modified radical mastectomy, and b) radical mastectomy.

- (a) **Modified radical mastectomy:** When treating early stage breast cancer, the goal is to remove all or most of the tumour. One of the main surgical procedures is called a modified radical mastectomy (MRM), which is the most common procedure in treating breast cancer (Meric et al., 2003; Veronesi et al., 2002). This procedure involves the removal of the entire breast, including the skin, areola and nipple as well as the axillary lymph nodes, but not the breast muscles.
- (b) **Radical mastectomy:** Is the most extensive type of mastectomy which involves the removal of all of the breast tissue along with the nipple, lymph nodes under the arm and chest wall muscles under the breast (American Cancer Society, 2013; Gregorio, Jimenez, Rodriguez, & Borda-Mas, 2013).

Because of the severity of this procedure the radical mastectomy comprises more alteration and change to the breast cancer patient's appearance than that of a lumpectomy or modified radical mastectomy (Haber et al., 1995).

#### 2.2.4.1.3 Radiation Therapy

Radiation, like surgery, is a loco regional therapy for conditions both malignant and benign (Haffty, 2009). Radiation can be explained as high energy X-rays that are aimed at the breast, chest wall and when necessary, at nearby areas that still contain lymph nodes, to destroy cancer cells. Side effects occur because radiation can also damage healthy cells and tissues near the treatment area such as reddening of the skin, discomfort and swelling of the breast and tiredness (Haber et al., 1995). For patients not undertaking chemotherapy directly after surgery, radiation treatment should start only after adequate healing of the wound and not before three weeks after surgery (Haffty, 2009).

#### **2.2.4.2 Systemic Treatments**

Systemic therapy is meant to treat the body and uses medications to target and destroy cancer cells that have spread beyond the breast. Chemotherapy and hormonal therapy (oestrogen-blocking medications) are examples of systemic treatments. Systemic therapy may precede local therapy, then it is called neo adjuvant therapy, or it can follow local therapy, and is called adjuvant therapy (Runowicz et al., 2016). Most people with breast cancer benefit from both local and systemic treatment. Systemic treatments indicate treatments to the whole body through the bloodstream and are classified as either chemotherapy or hormonal therapy and biological agents (Runowicz et al., 2016).

##### **2.2.4.2.1 Chemotherapy**

Chemotherapy is a drug treatment that uses powerful chemicals to destroy fast-growing cells in the body or by stopping the division of cancer cells. Chemotherapy is administered to control suspected micro metastatic disease (Haber et al., 1995). Early stage breast cancer patients who are at risk for systemic metastases are progressively treated with adjuvant chemotherapy (Haffy & Wilson, 2009; Recht et al., 1996). Adjuvant means additional or secondary treatment given after the primary treatment to enhance or extend the primary therapy's effect (e.g. as in chemotherapy's addition to a surgical regimen). Adjuvant therapy may include chemotherapy, radiation therapy, hormone therapy, targeted therapy, or biological therapy. Adjuvant chemotherapy for early stage breast cancer is administered before radiation therapy (Haffy & Wilson, 2009).

The aim of chemotherapy is to decrease the total number of cancer cells, but because chemotherapy is not cell selective it will also eradicate all rapidly dividing, healthy cells, including hair cells, therefore all the bodily hair will fall out as a side-effect of chemotherapy. Treatments can be dispensed from 12 weeks to one year (Haber et al., 1995) and be administered by mouth, injection or infusion depending on the type and stage of the cancer (American Cancer Society).

Another form of chemotherapy is called palliative chemotherapy. Palliative is a type of chemotherapy that is given specifically to address symptom management

without expecting to significantly reduce the cancer. The aim of palliative chemotherapy is to ease symptoms and prolong life without curing the patient.

#### **2.2.4.2.2 Hormonal Therapy**

Breast cancer is often hormonally sensitive and tumour cells possess both oestrogen and progesterone receptors (Col, Kim, & Chlebowski, 2005). A woman's ovaries are the main source of the hormone *oestrogen* until menopause. After menopause, smaller amounts are still made in the body's fat tissue, where a hormone made by the adrenal gland is converted into oestrogen. Oestrogen then promotes the growth of cancers that are hormone receptor-positive (Kuo et al., 2008; American Cancer Society, 2013). According to the American Cancer Society (2016), two out of three breast cancers are hormone receptor-positive.

Hormone treatment is another form of systemic therapy and is most often used as an adjuvant therapy to help reduce the risk of the cancer coming back after surgery for hormonally sensitive breast cancer patients of all ages (Deane, 2008; Haber et al., 1995; Haffty, 2009). Hormone therapy also minimises mortality within this cancer population (Brem & Kumar, 2011).

Most types of hormone therapy for breast cancer either lower oestrogen levels or stop oestrogen from acting on breast cancer cells. This kind of treatment is helpful for hormone receptor-positive breast cancers (American Cancer Society, 2014). In spite of all the positive outcomes of hormone therapy there are also negative side-effects. Oestrogen is the major hormone in sexual functioning, playing a key role in arousal, peripheral sexual response and pelvic sexual response. A decrease in oestrogen levels causes early and spontaneous menopause, dyspareunia and reduced sexual response (Kuo et al., 2008; Brem & Kumar, 2011). The two most dominant hormonal therapies are:

- **Tamoxifen**

Tamoxifen is a hormonal treatment that blocks oestrogen receptors in breast cancer cells, it stops oestrogen from binding to them and telling the cells to grow and divide. For women with hormone receptor-positive invasive breast cancer, Tamoxifen can be given in pill form for five to ten years after surgery to lessen

changes of the cancer recurring and helping patients live longer. It also reduces the risk of a tumour in the other, healthy breast. Tamoxifen acts by stopping cell growth (Haber et al., 1995; Davies, McGale, Peto, & Davies, 1998; Powles, 2013).

Tamoxifen is a drug mainly used for women who have not yet gone through menopause (Fisher et al., 1998; Haber et al., 1995). The most common side effects of Tamoxifen include fatigue, hot flushes, and vaginal dryness or discharge, and mood swings (American Cancer Society, 2014), which result ultimately in a reduction in sexual functioning (Krychman, Pereira, Carter, & Amsterdam, 2006; Mortimer, Boucher, Baty, Knapp, Ryan, & Rowland, 1999). Tamoxifen is a medication that has proven its efficacy in reducing tumour recurrence and prolonging survival when administered as postoperative adjuvant therapy in breast cancer pre-menopausal patients (Fisher et al., 1998).

- **Adjuvant Aromatase Inhibitor Therapy (AIs)**

Aromatase inhibitors are the preferred hormone treatment for women with breast cancer who have already gone through menopause as oppose to the (often younger) pre-menopausal breast cancer patients (Mok, Juraskova, & Friedlander, 2008). This therapy works by blocking an enzyme called aromatase in fat tissue that is responsible for making small amounts of oestrogen in post-menopausal women. AIs cannot stop the ovaries from making oestrogen; therefore this therapy is only effective in women whose ovaries aren't working, either due to menopause, or side-effects of treatments. AIs are taken daily as pills (Derzko, Elliott & Lam, 2007). The presence of postmenopausal gynaecological symptoms such as vaginal dryness and dyspareunia has been reported to influence the quality of life of women taking AIs. If not managed appropriately, these symptoms may result in sexual dysfunction, which can in turn affect a woman's quality of life (Mok et al., 2008).

### **2.2.5 Cancer treatment side-effects**

Breast cancer treatments can result in various physiological and psychological side-effects that can have a direct influence on the psychological well-being of this population. The most prominent and relevant psychical side-effects with psychological impacts will be discussed here.



### **2.2.5.1 Physical side-effects**

Recent years have seen exceptional advances in clinical oncology with an explosion of knowledge in breast cancer treatments which offer breast cancer patients better possibilities and expectations for cure and longer and healthier lives (Fallowfield & Jenkins, 2015; Weis, Poppelreuter & Bartsch, 2009). Apart from the positive influence of the treatment modalities for cancer (adjuvant chemotherapy, hormone therapy, radiation therapy and surgery) there is also growing evidence that these modalities can result in long-term functional deficits and reduced health-related quality of life and can even compromise the prognosis of the illness (Oers, 2013; Van Oers & Schlebusch, 2013; Weis, Poppelreuter, & Bartsch, 2009).

Lymphedema, fatigue, vasomotor complaints, sexual dysfunction and cognitive impairment are the five most common and unpleasant physical complications of breast cancer treatment (Mok et al., 2008). Brem and Kumar (2011) add reduced cardiac function, nausea and vomiting, alopecia, pain, weight gain, ataxia, (the loss of full control of bodily movements), asthenia, (abnormal physical weakness or lack of energy), spontaneous menopause and peripheral neuropathy to the list. The majority of cancer-related physical side-effects are mostly acute, but some symptoms like lymphedema, pain, hormonal changes and cognitive dysfunction and sexual dysfunctions can be chronic or even permanent which can incapacitate the quality of life of the breast cancer survivor (Brem & Kumar, 2011; Fallowfield & Jenkins, 2015).

#### **2.2.5.1.1 Lymphedema**

Surgical removal of the axillary lymph nodes during a lumpectomy or mastectomy can cause lymphedema, which is a chronic side-effect. Lymphedema means swelling of the arm, hand or (very rarely) the breast area caused by a build-up of lymph fluid in the surface tissues of the body caused by damage to the lymphatic system. This damage can occur either through surgery and/or radiotherapy to the lymph nodes under the arm (axilla) and surrounding area (Dean, 2008; Gottrup, Andersen, Arendt-Nielsen, & Jensen, 2000).

Axillary lymph node dissection can generate extensive arm morbidity with lymphedema which includes pain, loss of sensation, numbness and loss of strength and mobility which did not necessarily lessen over time. The pain can also manifest in the shoulder and not just the arm and some breast cancer patients report worse results after the axillary surgery in terms of pain and discomfort than the surgery of the breast itself (Brem & Kumar, 2011; Fallowfield & Jenkins, 2015). A study done by Rosenberg and co-workers (2012) has found lymphedema to negatively affect the psycho-social well-being of the breast cancer patient, but often only develop at a later stage during the process of treatment. Lymphedema, as a cancer treatment side-effect, can also potentially impair sexual quality of life because of the influence on the patients' body image (Dean, 2008; Rosenberg et al., 2012) and according to Kuo and co-workers (2008) lymphedema can affect comfort during sexual activity and may make sexual intimacy challenging or even painful.

#### **2.2.5.1.2 Cancer-related fatigue**

Fatigue is a common medical complaint amongst a variety of illnesses and one of the most common symptoms in breast cancer survivors. It has been estimated that this problem can affect up to 70% of cancer patients during chemo- and radiotherapy or after surgery (Dimeo, Schwartz, Wesel, Voigt, & Thiel, 2008). According to Fallowfield and Jenkins (2015) fatigue has replaced nausea and vomiting because of effective anti-nausea medication as the biggest post-treatment problem in breast cancer patients. Although fatigue is usually acute, up to 30% of breast cancer patients report persistent fatigue throughout the first 10 years post-treatment, even patients in complete remission (Berger et al., 2015; Dimeo, 2008; Fallowfield & Jenkins, 2015).

Fatigue is defined as a feeling of weariness, tiredness or lack of energy and influences different dimensions of the patient's life (Fernando, 2001). Chronic fatigue syndrome share some features with cancer-related fatigue, but should be considered separate entities (Berger et al., 2015; Vahdaninia et al., 2010). In comparison with other forms of fatigue, cancer-related fatigue is more rapid in onset, more persistent and energy draining, and more severe (Bren & Kumar, 2011; Dean, 2008; Murray, 2010). Fatigue has been defined as the most

distressing and incapacitating symptom of all the cancer treatment related side-effects and is predominant in patients during and after cancer treatment (Johns, Brown, Beck-Coon, Monahan, Tong, & Kroenke, 2015). The degree of fatigue varies according to the type of cancer and specific treatment modality. Chemotherapy, surgery, radiation therapy and hormone therapy all have the capacity to cause fatigue which can persist many years into survivorship (Berger et al., 2015; Johns, 2015; Oers, 2013).

Cancer patients may describe their experience of fatigue in three different ways:

- (a) Mental fatigue: an absence of concentration and loss of memory.
- (b) Volitional fatigue: an inability to initiate tasks or a tendency to elude social contacts and activities, and
- (c) Physical fatigue: a tiredness and easy exhaustion from activities demanding physical effort.

While the first two forms of fatigue may primarily indicate psychological disturbance and increase mental distress, the physical fatigue experienced by cancer patients usually has an organic etiology (Fernando, 2001). Several biological, psychological, and social factors have been proposed as explanations for the origins of fatigue in this framework for in most cases, fatigue has a multifactorial genesis (Fernando, 2001; Johns, Brown, Beck-Coon, Monahan, Tong, & Kroenke, 2015).

- **Fatigue as a biological phenomenon**

Recent studies suggest that fatigue may originate from alterations in the muscular energetic systems caused by cancer and its treatments (Fernando, 2001; Johns et al., 2015). Several etiologic mechanisms have been hypothesised to explain the development of fatigue in cancer patients which include the following: pain, electrolyte and fluid disturbances, anaemia, changes in nutritional status, weight loss, changes in the concentration of metabolically active molecules (as a result of the interaction between the tumour and the host defence system), medicines with action on the central nervous system and sleep disturbances (Fernando 2001).

The most critical factor in the regulation of energy production is the supply of oxygen to the mitochondrial crests (Fernando, 2001). Sufficient oxygen delivery to the cells requires the reliability of all links in a complex chain of organs and functions regulating oxygen absorption, transport, and release. Several functional and anatomic changes due to cancer treatment can affect the oxygen supply to the cells (Fernando, 2001). Chemotherapy, as a breast cancer treatment, can damage bone marrow and consequently impair the production of red blood cells, resulting in anaemia which decreases the oxygen transport capacity of the blood and therefore the oxygen supply to the cells. Because the maximal oxygen uptake is severely impaired as a consequence of the cancer and its treatment, the oxygen transport systems can be overwhelmed even by normal daily activities like climbing stairs, walking, or housekeeping (Fernando, 2001). Cancer patients then not just suffer from fatigue but also from an incapacitation of physical performance (Johns et al., 2015).

Another reason for fatigue can be impaired muscular functioning, which can be worsened by the lack of activity during in-hospital treatment. Prolonged bed rest results in a substantial loss of muscle mass and plasma volume and a reduction of cardiac output that can influence physical capacity. After discharge, patients need to make greater efforts to carry out normal activities (Fernando, 2001).

- **Fatigue as a psychological phenomenon**

Regardless of the strong underlying biological element of cancer-related fatigue, there is a clear association between fatigue and psychological distress (Fernando, 2001; Johns et al., 2015). It is not only physical performance that is affected by fatigue, but also cognitive functioning. Cancer patients report fatigue as a combination of symptoms involving an incapability to carry out physical action, tiredness, lack of interest and impairment of short-term memory, attention, or concentration. These complaints are commonly related with sleep disturbances, as in hypersomnia or insomnia (Dimeo, Schwartz, Wesel, Voigt, & Thiel, 2008). Cancer-related fatigue impairs activities of daily living which can contribute to anxiety, depression and poor overall health-related quality of life (Dean, 2008; Fallowfield & Jenkins, 2015; Johns et al., 2015; Vahdaninia, 2010). This restrictions through fatigue on quality of life exist across the whole cancer and

treatment trajectory and has been characterized as overwhelming and persistent (Johns et al., 2015).

On the basis of its different features it has been proposed that fatigue is a syndrome rather than an isolated complaint or symptom. For many patients, fatigue is a severe and limiting problem that not only impairs the physical and mental performance, but can prevent the patient from working or carrying out regular daily activities that result in a substantial reduction of quality of life (Dimeo et al., 2008; Fallowfield & Jenkins, 2015).

### **2.2.5.1.3 Cancer-related pain**

Tumour-related pain syndromes have already been recognized and accepted in the past, but currently long-term-treatment-related pain etiology is also being acknowledged because of the increasing numbers of cancer survivors suffering from pain syndromes. These tumour- and treatment pain syndromes are often typified by the type of treatment administered, but as most patients receive multiple modalities, the pain syndromes may reflect a combined effect of treatments e.g. radiation affects, chemotherapy and surgery (Paice & Ferrell, 2011).

- **Neuropathic pain**

Neuropathic pain is defined as a complex, chronic pain that is generally accompanied by tissue injury (Backonja, 2003). Neuropathic pain can be described as a direct consequence of a wound or disease affecting the somatosensory system (Geber, et al., 2009). A change in function, chemistry, and structures of neurons (neural plasticity) trigger the production of the altered sensitivity characteristics of neuropathic pain (Vranken, 2009). Neuropathic pain or nerve pain can last up to three months after surgical and non-surgical treatments including radiation- and chemotherapy (Macdonald, Bruce, Scott, Smith, & Chamber, 2005). Chronic pain can be defined as pain persisting beyond the normal healing time of three months and chronic pain symptoms may be mild and not needing treatment or it can be severe and significantly restricting quality of life (Blunt, & Schmiedel, 2004; Geber et al., 2009).

- **Post mastectomy pain syndrome (PMPS)**

Post mastectomy pain, which is classified as a chronic neuropathic pain syndrome, can be caused by tissue injury and can affect women permanently after a mastectomy or lumpectomy (Brem & Kumar, 2011). Post-mastectomy pain syndrome is a recognized complication of breast surgery, although little is known about the long-term outcome of this chronic pain condition (Macdonald et al., 2005). In a study done by Gottrup and co-workers (2000) they have found that as many as 75% of women who underwent breast cancer treatment report chronic pain. Although the exact mechanism of development of PMPS is not known, it is possibly a neuropathic pain condition which is caused by damage to the nerves in the axilla and/or the chest wall during breast surgery (Vilholm, Cold, Rasmussen, & Sindrup, 2008).

Persistent pain after a mastectomy was first described during the 1970s, characterized as a typical neuropathic pain consisting of a dull, burning or shooting pain evoked by pressure and deep blunt pain. The pain is often sited in the frontal chest, shoulder, arm and axilla that worsened by movement of the shoulder cord (Blunt et al., 2003; Dean, 2008; Macdonald et al., 2005; Vilholm et al., 2008). PMPS can develop shortly after surgery or up to several months after surgery and can persist for years. The prevalence of PMPS has been shown to be higher after a lumpectomy than after a mastectomy. Axillary lymph node dissection can also result in pain and did not necessarily lessen over time which then counts as chronic pain (Brem & Kumar, 2011; Sarenmalm, Ohlen, Johnsson, & Gaston-Joahansson, 2007; Vilholm et al., 2008). High levels of pain after a mastectomy, lumpectomy or lymph node dissection can significantly impair the quality of life of the breast cancer patient (Gregorio, Jimenez, Rodriguez & Borda-Mas, 2013).

Risk factors for persistent PMPS include younger age, heavier weight, previous breast surgery and tumour located in the upper lateral quarter (Vilholm et al., 2008). Younger patients tend to have larger tumours which explain the more serious postoperative and long-term pain (Macrae, 2008). Macdonald and colleagues (2005) suggest that the intensity of PMPS can decrease over time, which can be explain in that the breast cancer patient might develop adaptation mechanisms or strategies to learn to cope with persistent pain. Constant pain

influences all aspects of quality of life and severely influences the patient's ability to endure treatment, return to health as a cancer survivor, or achieve a peaceful death (Paice & Ferrell, 2011).

Pain often co-occurs with cancer-related fatigue in a complex relationship and can be seen as part of a symptom cluster. In a study done by Lueboonthavatchai (2007) pain and fatigue were the two leading symptoms reported by cancer patients. Pain itself can be exhausting and can conduct fatigue by interfering with sleep and decreasing abilities for physical activity (Berger et al., 2015). Pain is often concurrent with psychological distress and pain and fatigue as combination can be a risk factor for developing anxiety and depression in breast cancer survivors (Brem & Kumar, 2011; Lueboonthavatchai, 2007; Vahdaninia, 2010).

#### **2.2.5.1.4 Cognitive impairment**

Mild cognitive complaints following chemotherapy is one of the most commonly reported post treatment symptoms by breast cancer survivors. This deterioration in cognitive function is generally referred to as “chemobrain” or “chemo fog” (Boykoff, Moieni, & Subramanian, 2009; Brem & Kumar, 2011; Denlinger et al., 2014). According to O’Farrell and colleagues (2013) there is growing evidence that the neurotoxicity of chemotherapy contributes to cognitive changes. Chemo-fog or chemo-brain reflects the fact that the symptoms of the cognitive dysfunction are usually mild to moderate and generally not comprehensive. The specific areas of cognition that are affected are: attention, concentration and memory, speed of information processing, verbal and visual memory, multitasking and ability to organize information (Brem & Kumar, 2011; Brezden, Phillips, Abdoell, Bunston, & Tannock, 2000; Fallowfield, 2015; Raffa, 2010). This phenomenon of cognitive incapacitation was largely unacknowledged by the medical society until recent years (Boykoff et al., 2009). Apart from chemotherapy, evidence suggests that other treatment modalities such as endocrine therapy and radiation therapy can also be associated with cognitive impairments (Brem & Kumar, 2011; Denlinger et al., 2014).

A recent controlled study (pre- and post-chemotherapy) of neuropsychological testing and magnetic resonance imaging (MRI) found changes in the brain’s grey matter which they associated with chemotherapy, suggesting a physiological basis

for cognitive disturbance. Higher memory complaints were statistically significantly associated with the combination of chemotherapy and radiation treatment and not chemotherapy alone (Ganz et al., 2013). This cognitive impairment can last anywhere from six months to ten years following treatment (Brem & Kumar, 2011) but Weis and colleagues (2009) claim that there is a significant improvement in the cognitive condition and self-assessment as time elapsed after the end of treatment. Cognitive dysfunction can be either a side-effect of some of the cancer treatments or it can be a symptom of a major depressive disorder in the form of diminished ability to pay attention and concentrate and incapacity of short term memory (Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> edition). In the past decade, a growing bulk of evidence has suggested patients suffering from major depression present with cognitive disorders such as impairment in attention, working memory, and executive function, including cognitive inhibition, problem- and task-planning (Marazziti, Consoli, Picchetti, Carlini, & Faravelli, 2010).

Breast cancer survivors report diminished quality of life and daily functioning as a result of chemobrain that affect them emotionally, interpersonally and economically and can also increase stress, especially in a professional environment. In the light of the above, more research needs to be conducted on the psycho-social consequences of post treatment symptoms, especially cognitive impairment, in order to understand and support this cancer population better (Boykoff et al., 2009).

#### **2.2.5.1.5 Nausea and vomiting**

Nausea is a protective reflex against the ingestion of toxins and is defined as a subjective phenomenon of an unpleasant sensation in the epigastrium and in the back of the throat that may or may not culminate in vomiting (Dibble, Israel, Nussey, Luce, 2004). Vomiting is the mechanical result of neuro-physiological induced rhythmic, coordinated, diaphragmatic, chest wall and abdominal muscle action leading to expulsion of gastric contents through the mouth (Dibble et al, 2004). The two main treatment modalities that can cause nausea and vomiting are chemotherapy and radiotherapy.

- **Chemotherapy induced nausea and vomiting**



The function of cytotoxic/chemotherapy is to damage cells. Therefore it makes perfect sense for the body to eject them as soon after ingestion as possible. From the body's point of view, they should simply be avoided, and it is not surprising that the experience of chemotherapy induced nausea and vomiting is powerfully aversive (Antonarakis & Hain, 2003). Although the management of nausea and vomiting as unpleasant side-effects of chemotherapy has improved, it still remains to be amongst the most feared and commonly reported side-effects by cancer patients. Because of the improvement of nausea and vomiting through antiemetics, concern has shifted now to more subtle and potentially chronic problems such as fatigue, menopausal symptoms and cognitive dysfunction, with fatigue as the biggest post-treatment problem of cancer (Fallowfield & Jenkins, 2015; Fan et al., 2005).

The probability that nausea and vomiting will develop after chemotherapy depends on several factors. Two of these factors are sex and age, with female cancer patients and younger patients being more likely to develop nausea and vomiting (Hesketh, 2008). The occurrence of chemotherapy induced nausea and vomiting will further be determined by the dose and type of the chemotherapeutic agents administered and by individual patient characteristics, therefore will differ from patient to patient (Rapoport et al., 2010; Roscoe et al., 2004; Schnell, 2003). Chemotherapy-induced nausea and vomiting can be broadly categorized as anticipatory, acute or delayed (Schnell 2003).

- (a) **Anticipatory nausea:** New attention has been dedicated to the occurrence of nausea and vomiting in anticipation of chemotherapy (Morrow & Dobkin, 1988). Anticipatory nausea means it occurs before the start of chemotherapy in anticipation of the treatment and develops in 8 – 20% of cancer patients (Ryan et al., 2012). In a study done by Morrow and co-workers (1988) at least 25% of their study population who underwent chemotherapy has developed anticipatory nausea and vomiting by the time of their fourth treatment. Patients who have a high pre-treatment expectation of nausea are more likely to have nausea after chemo. Especially patients under the age of 50 years who are treated with potentially emetic chemotherapy (emetic meaning a substance causing

vomiting) and who experienced upsetting nausea and vomiting after previous treatments, appear to be at risk of developing anticipatory nausea and vomiting for further treatments (Hesketh, 2008; Morrow & Dobkin, 1988).

- (b) **Acute nausea:** Begins within minutes of chemotherapy administration and resolves or settles within 24 hours (Antonarakis & Hain, 2004; Ryan et al., 2012).
- (c) **Delayed nausea:** Occurs from 24 hours up to five days post-chemo and can persist for several days (Antonarakis & Hain, 2004; Ryan et al., 2012). Chemotherapy-related nausea and vomiting seemed to cause substantial physical, psychological and functional distress for cancer patients and therefore it is important that patients with an increased risk for nausea should be identified and treated in advance, e.g. those patients with a history of nausea (Enblom, Axelsson, Steineck, Hammar, & Börjeson, 2009; Foubert & Vaessen, 2005; Martin, Rubenstein, Kim, & Osoba, 2003).

- **Radiotherapy induced nausea and vomiting**

Although many studies have focused on chemotherapy induced nausea, less attention has been paid to radiotherapy-induced nausea (Enblom et al., 2009; Maranzano et al., 2005; Tonini et al., 2003). The incidence of nausea during radiotherapy varies depending on the site being treated, for example, total body irradiation can cause nausea more often (between 80 - 100% of patients) than radiation of specific fields (39%). The size of the radiotherapy field also influences the risk for nausea, e.g. if the size of the radiotherapy field are over 400 cm<sup>2</sup> the risk for nausea is bigger. A single dose treatment more often leads to nausea although with shorter duration than fractionated treatments. Radiotherapy targeted to the pelvic or abdominal field indicated an increased risk of nausea. Patients younger than 40 years were more at risk for radiotherapy related nausea (Enblom, et al., 2009). These authors also found that earlier experience of nausea in other circumstances e.g. during previous chemotherapy, implied and heightened risk for nausea which compares with previous literature (Feyer, Stewart, & Titlbach, 1998; Feyer et al., 2005). Although radiotherapy induced nausea is usually considered to

be less problematic than chemotherapy induced nausea (Roila, Ciccarese, Palladino & De Angelis, 1998) the results of Enblom and colleagues (2009) have shown that nausea during radiotherapy may affect the patients' daily lives in several negative ways. Occurrence and severity of nausea and vomiting depend (as with chemotherapy-related nausea and vomiting) also on patient-related factors as in general health of the patient, age, recent or concurrent chemotherapy, psychological state and tumour stage (Roila, et al., 2010).

#### **2.2.5.1.6 Alopecia**

Alopecia means chemotherapy-induced hair loss which may occur throughout the body, including the head, face, arms, legs, underarms, and pubic area (Lemieux, *et al.*, 2008). Alopecia, ranging from partial hair loss to total hair loss, is a common side effect of most chemotherapy combinations presently used in breast cancer treatment (Lemieux, Maunsell, & Provencher, 2008; van den Hurk, Mols, Vingerhoets, & Breed, 2010). The probability of alopecia relates to the type of drug used and its schedule of administration. Alopecia ranks amongst the first three most important and traumatizing side-effects of cancer treatment. Cancer patients describe hair loss in recent studies as a problem and extremely distressing (Kim et al., 2012; Lemieux et al., 2008; Van den Hurk et al., 2010). Lemieux and colleagues (2008) also found that a small percentage of their patients have even refused chemotherapy because of the risk of alopecia.

Hair plays an important role in the appearance and uniqueness of an individual and is a symbol of identity and personality. Kim and colleagues (2012) found in a study that all their participants thought that appearance was important and that they had negative perceptions about alopecia. They also reported that they were not well prepared for alopecia and experienced substantial physical, psychological and social distress. They summarised their results by replying that the lack of information regarding alopecia and limited social support combined with negative images of cancer made it hard to overcome the trauma of hair loss and prevented them from usual daily activities resulting in poor quality of life. Boehmke and colleagues (2005) found that even if hair loss was expected, women still found it a traumatic experience and felt it changed their sense of self.

There is a link between hair and thoughts of femininity and masculinity, attractiveness and sexuality. Alopecia can change a person's perception of her sense of self and sexual self-esteem and some researchers found that this change in self-perception can cause a decline in sensuality and sexuality (Kim et al., 2012; Lemieux, 2008; Munstedt, Manthey, Sachsse & Vahrson, 1997). This change of perception can then result in a change in sexuality and often in sexual functioning. Alopecia not only affects a person's self-image and sexuality, but also incapacitates her social activities and interactions, with some patients reporting feelings of shame because of their hair loss (Lemieux, 2008; Kim et al., 2012). Rossman (2004) said for women in particular, hair loss involves a confrontation with the fatal nature of cancer, while for men; it is more of a normal and inevitable consequence of treatment. Lemieux and co-workers (2007) however, experience a lack of substantial evidence of how alopecia affects male cancer patients and regard this as a gap in this research field.

Alopecia can also stigmatize cancer patients by changing their identity from a healthy person into a cancer patient where they often experience a loss of privacy because it makes society conscious of their illness and chemotherapy. For cancer patients alopecia is furthermore a visible and constant reminder of their illness and even in some cases, mortality (Kim et al., 2012; Van den Hurk et al., 2010). Consequently, regarding the above information, alopecia causes emotional suffering and may lead to personal, social and work related problems which can contribute to a reduced quality of life (Kim et al., 2012; Lemieux, 2008; Van der Hurk et al., 2010). For some patients, however, the negative effects of hair loss can be lessened by the psychological process of adaptation and for many other patients, physical characteristics became less important as physical features became less important as measures of worth and living itself became more important (Wagner & Bye, 1979).

Although significant advances have been made in controlling the impact of chemotherapy-related side-effects, especially in the field of nausea and vomiting through anti-nauseous drugs and symptom management, alopecia is still a major side-effect with no successful preventive intervention as yet. With regard to alopecia, wigs are one strategy to camouflage and hide hair loss (whether it is

partially or complete) and over the years the quality of wigs has improved drastically. Today the possibilities for head covering are modern and more extensive and patients are nowadays often advised about managing alopecia before starting their chemotherapy (Rossman, 2004; Van den Hurk et al., 2010). If baldness represented being sick, new hair after alopecia represented hope, optimism, faith and a new life. In a study done by Kim and colleagues (2012) many participants have revealed that they felt that the suffering and difficulty was over when they saw newly growing hair and that that looking at new hair made them feel alive and happy.

#### **2.2.5.2 Psychological side-effects**

The last three decades have seen some extraordinary developments in breast cancer treatment and an explosion of knowledge regarding the genomics and molecular biology which have led to an increased number of chemotherapeutic options that is offering women greater expectations and hope of cure or longer, good quality survival. But nothing comes without a price, and despite these creditable therapeutic breakthroughs, substantial psycho-social harmful side-effects continue to be created by the diagnosis and aggressive treatment modalities of breast cancer (Borras et al., 2014; Fallowfield & Jenkins, 2015; Spiegel, 2008).

Psychological distress can be defined as a multifactorial, unpleasant emotional experience of a psychological (cognitive, behavioural and emotional), social, and/or spiritual nature and is an extensive concern associated with the invasive nature of breast cancer and its treatment. According to Nekolaichuk and co-workers (2011) approximately one in three breast cancer patients will experience noteworthy psychological distress at some stage during the course of their breast cancer. Breast cancer patients especially are inclined to be psychologically fragile because of the stress of the diagnosis, the draining and long treatments, pain, unpredictability of the course of the treatment and the chronicity of the disease (Brem & Kumar, 2011; Van Oers & Schlebusch, 2013). Beginning with the diagnosis of breast cancer, this disease involves a long and upheaval process of psychological and social adjustments to this new and unforeseen experience that impacts a woman's life and that of her family (Travado & Reis, 2013).

Psychological trauma can be caused by events which are unexpected and sudden and in which the individual identifies a dramatic loss of personal control and personal safety (DSM-IV). Patients, who are diagnosed with a life-threatening illness such as cancer, are confronted with a sense of their own mortality which often causes acute psychological stress for them and their families (Brennen, 2001; Spiegel & Rodrigues, 2008). Unfortunately psychological distress may interfere with a person's ability to cope effectively with the physical symptoms of cancer and cancer treatment (Nicolas, 2013).

According to Livneh (2001) most researchers and clinicians would agree that psychosocial adaptation to chronic illness and disability results in a long term complex, active and continuously evolving process. Therefore, many patients are at risk of developing psychological dysfunctions that might lead to premature mortality and morbidity and consequently can compromise their quality of life (Brem & Kumar, 2011). This theory was confirmed by a meta-analysis of 31 prospective studies done by Davis and co-workers (2011) where they found a 25% higher mortality rate for patients with cancer suffering from depressive symptoms and a 39% higher mortality rate for patients presenting with major depression after adjusting for prognostic components. Cancer is regarded as a disease which not only disturbs a person's physique, but also alters his/her self-image, sexuality, interpersonal relationships, family dynamics and social roles, even when the prognosis is not life threatening (Surbone, Baider, Weitzman, Brames, Rittenberg, & Johnson, 2010).

Studies have shown that the prevalence of psychological distress among breast cancer patients is high and that this population is at risk of developing severe mood disorders, such as depression and/or anxiety, which are the two most common psychiatric disorders in this population (Dolbeault et al., 2009; Lueboonthavatchai, 2007; Navari, et al., 2008; Vahdaninia, et al., 2010), as well as symptoms of a post-traumatic stress disorder (Ang, 2011; Brennen, 2001; Dolbeault et al., 2009). In the light of the above mentioned the psychological needs of cancer patients have been, and will carry on being, a subject ripe for advocacy by the cancer care professionals and especially that of the psycho-oncologists (Nicolas, 2013).

### 2.2.5.2.1 Depression

Taking into consideration that depression in particular has a strong and intricate relationship with cancer and that 10% to 25% of breast cancer patients potentially are at risk of developing depression, it is important to understand and recognize the symptomatology of depression (Nekolaichuk et al., 2011; Reyes-Gibby et al., 2012).

- **Diagnostic criteria of depression**

The detection of depressive symptoms and syndromes in patients with cancer is of value both to the patient, because his/her mental distress may respond to treatment, and to the clinician, for some of the clinical difficulties in the diagnosis and treatment of the patient may be explained and reduced by the knowledge (Endicott, 1984). The diagnostic criteria of a Major Depression and Major Depression due to another medical condition according to the DSM-5R are:

- A) Five or more of the following symptoms have been present during the same 2 week period and represent a change from previous functioning and at least one of the symptoms is either a depressed mood or a loss of interest or pleasure.
  - (a) Depressed mood most of the day, nearly every day with feelings of sadness or hopelessness.
  - (b) Markedly diminished interest or pleasure in all or almost all activities.
  - (c) Significant weight loss or weight gain.
  - (d) Insomnia or hypersomnia nearly every day.
  - (e) Psychomotor agitation or retardation.
  - (f) Fatigue or loss of energy nearly every day.
  - (g) Feelings of worthlessness or excessive or inappropriate guilt nearly every day.
  - (h) Diminished ability to think or concentrate.
  - (i) Recurrent thoughts of death (and not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan of committing suicide.

- B) There is evidence from the history, physical examination, or laboratory findings that the disturbance is the direct pathophysiological consequence of another medical condition.
- C) The disturbance is not better explained by another mental disorder.
- D) The disturbance does not occur exclusively during the course of a delirium.
- E) The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Apart from using the DSM-5R to make the diagnosis of a depressive episode, psychologists and clinicians also use the ICD 10 code to strengthen and describe a diagnosis. The International Classification of Diseases, Tenth Revision, Clinical Modification (ICD 10 – CM) is a system used by physicians and other healthcare providers to classify and code all diagnosis, symptoms and procedures recorded in conjunction with hospital care which was published by the World Health Organisation (WHO). Health care professionals use ICD-10 codes to assist them in the storage and retrieval of diagnostic information, e.g. Post-Traumatic Stress Disorder (DSM-5R) F43.10 (ICD-10) or an Adjustment Disorder with depressed mood (DSM-5R) and ICD-10 of F43.21 (Quan et al., 2005). Apart from the diagnosis of a Major Depression, according to the DSM-5R and an ICD-10 code of F32, the DSM 5R also refers to depression during an illness as a Major Depression due to another medical condition, with an ICD-10 code of F 6.31. In making this diagnosis, full criteria for a Major Depression are met, except criterion C. Apart from the theoretical use of coding, ICD-10 coding is especially important for billing a patient, for medical aids (in South-Africa) only accept ICD-10 codes when processing an invoice.

- **The impact of depression on the breast cancer patient**

The prevalence of depression among breast cancer patients is generally much higher than the general population. Stressful life events are strongly related to depression and a cancer diagnosis have been defined in the literature as one of the most stressful and traumatic medical diagnoses that a person can receive (Meier, 2010; Reyes-Gibby et al., 2012). Breast cancer diagnosis and treatment



have an overwhelming and acute impact on a woman's physical, psycho-social and spiritual welfare consequently compromising her general quality of life.

The presence of cancer-related symptoms, painful treatments, the number of hospital admissions, reduced quality of life, recurrence or progression of the disease, uncertain mortality, fear of death, altered body image and sexual problems, all contribute to patients' experience of depression (Lueboonthavatchai, 2007; Mello et al., 2013; Reich et al., 2007; Vahdaninia et al., 2010). Nausea, fatigue, pain, tiredness, weakness and reduced energy are common symptoms found in breast cancer patients and can all act as predictors for anxiety and depression. Especially pain and fatigue, who are the two leading symptoms, reported by breast cancer patients, have a strong connotation with depression (Lueboonthavatchai, 2007; Vahdaninia et al., 2010). Cancer patients experience depression as feelings of sadness and hopelessness, sleep disturbance and loss of appetite, psychomotor retardation, withdrawal from social activities and heightened expectancy of pain (Mello et al., 2013; Van Oers, 2013). All of these symptoms could be either related to the cancer self, or could be symptoms of surgery, chemotherapy, radiotherapy or depression. Because of the overlapping of these somatic symptoms it can make the diagnosis of depression difficult which then leads to under-diagnosing and treating the depression, which can further complicate the treatment and outcome of the cancer (Lueboonthavatchai, 2007). Experiencing an episode of depression or anxiety soon after the diagnosis of, or during treatment of breast cancer, adds to the pain and suffering of the patients and the burden on the family (Meier, 2010).

Given the anticipated increase in the number of breast cancer survivors over the next decades, understanding the epidemiology of depression and its negative impact on quality of life during the time of treatment and the survival period, will have important clinical and community implications (Reyes-Gibby et al., 2012). Recent studies have found that about one in three cancer patients will experience significant emotional and psychological distress at some point during the course of their cancer and between 16% - 25% of breast cancer patients will develop a major depressive disorder (Nekolaichuk et al., 2011; Hopko et al., 2016). Despite the high prevalence of psychological morbidity and major depressive symptoms in

breast cancer survivors, it is often misdiagnosed and undertreated in health care services. Although cancer patients are known to have high percentages of psychological morbidity, they are low consumers of psychiatric care, particularly for clinically severe disorders. Gandubert and co-workers (2009) has identified this failure to detect breast cancer patients with psychological distress due to time constraints and the lack of communication between healthcare professionals and their patients. This occurrence is probably based on the common belief amongst clinicians that conditions such as anxiety and depression are 'normal' reactions to the diagnosis and treatment of cancer and the clinical postulation that such suffering will diminish over time. In a study done by Gandubert and co-workers (2007) 19.4% of the cancer group (different types of cancer were evaluated) reported feeling depressed. In the breast cancer group, depression was significantly higher comparing with other types of cancer. Poorly managed depression can lead to emotional suffering, anxiety and poorer quality of life which can cause intensification of physical symptoms, increased functional impairment and prevention of returning to a pre-morbid level of functioning (Fann et al., 2008; Meier, 2010; Reich, et al., 2007; Wong-Kim & Bloom, 2005).

Depression and symptoms of depression relates to poor adherence with recommended cancer treatment, tumour progression and mortality. All of these symptoms can lead to a deterioration of quality of life and an incapacitation of social and occupational functioning (Mello et al., 2013; Vahdaninia et al., 2010). It is imperative to monitor breast cancer patients for symptoms of depression or a depressed mood and provide means for treatment within the clinical oncology setting to guarantee a better quality for this cancer population (Reyes-Gibby et al., 2012). Prevention of depression or anxiety through early diagnoses is therefore a worthwhile goal (Hill et al., Meier, 2010).

Various factors predict depressive disorders in breast cancer patients. These factors include demographic aspects such as age, post-menopausal period, disease severity, level of patient disability, physical impairment, poor performance status and survival (Reyes-Gibby et al., 2012; Wong-Kim & Bloom, 2005). Pre-morbid psychiatric history is a well-known risk factor in developing depression during and after breast cancer and cancer treatment. A study done by Hill and co-

workers (2010) highlighted the vulnerability of women with previous episodes of depression and anxiety to further mental health problems during the year after diagnosis of breast cancer. Studies have shown that the frequency of depression in breast cancer patients is higher than in most cancers because menopause and oestrogen decline are related to (symptoms of) depression (Brem & Kumar, 2011; Fann et al., 2008; Navari et al., 2008). Especially women with Stage IV metastatic breast cancer, who face the likelihood of a foreshortened future, may be particularly at risk of poor mental health and depression (Low & Stanton, 2015). There are researchers who claim that risk factors for depression are rather related to the patient self and his/her relevant psychodynamics, as to the disease and the disease treatment which have implications on treating the symptoms of depression and the patient in general (Burgess et al., 2005; Reich et al., 2007).

- **Depression throughout the trajectory of breast cancer**

Although the American Society of Clinical Oncology Cancer Survivorship (ASCO) a cancer survivor define as any person who has received a cancer diagnosis from the point of diagnosis onward, the committee has chosen to use a more functional definition of survivorship, focusing on individuals who have successfully completed medicinal treatments or the individuals who have transitioned to maintenance or preventative therapy (Raque-Bogdan Hoffman, Ginter, Piontkowski, Schexnayder, & White, 2015; Surbone, Annunziata, Santoro, Tirelli, & Tralongo, 2013). For the benefit of this study a cancer survivor or survivorship will refer to a patient in full remission. The remission phase means a decrease in or disappearance of signs and symptoms of cancer. In partial remission means some, but not all the signs and symptoms of cancer have disappeared and complete remission means all the signs and symptoms of cancer have disappeared, although the cancer still may be in the body (NCI Dictionary of Cancer Terms).

Two different groups can be identified in terms of time frames and psychological distress (Henselmans, Helgeson, Seltman, de Vries, Sanderman, & Ranchor, 2010). The first group is the patients that experience distress right after the diagnosis of breast cancer and which are in the active treatment phase. The second group are the patients in the re-entry and remission phase. The re-entry phase is defined by different authors as the months from treatment completion

through 12 to 18 months (Bloom, Petersen & Kang, 2007; Henselmans et al., 2010; Stanton, 2012). The same researchers view long-term survivorship as beginning at least 5 years after diagnosis and completion of treatment. The remission phase can also be in the re-entry phase. According to Henselmans and co-workers (2010) there is also a group of breast cancer patients (36%) who appear to experience no distress at all.

- **Depression in the diagnostic phase and acute treatment phase**

Although studies have shown that women with breast cancer are highly exposed to developing major depression during the course of their illness (16% to 25%), it is believed that the level of psychological distress would be higher around the time of diagnosis and during active treatment (33%), specifically in the first year following the cancer diagnosis (Brem & Kumar, 2011; Burgess et al., 2005; Dolbeault et al., 2009; Henselmans et al., 2010; Hopko et al., 2016; Vahdaninia et al., 2010). There are a number of challenges that breast cancer patients endure during the period of diagnoses and the process of active treatment such as the continuous biological and psychological side-effects. These symptoms are particularly acute in the first few months after the cancer diagnosis and can affect the patients' lives through changes in their ability to function in daily activities such as work, relationships with others, or caring for themselves (Sohl, Levine, Case, Danhauer, & Avis, 2014). Illness invasiveness or how much a chronic illness, such as breast cancer, interrupts life domains, is an important concept in explaining why the same diagnosis and treatment leads to varied quality of life outcomes. There are different psychological reactions at different stages of the illness with denial, anger, uncertainty and anxiety often the most prominent emotions at the initial stage of diagnosis (Lueboonthavatchai, 2007; Liao, Chen, Chen & Chen, 2008; Mello et al., 2013). Authors like Wong-Kim and Bloom (2005) claimed that whether a breast cancer patient is in active treatment or not, did not exclusively predict depressive symptoms, instead the treatment side-effects such as the extent of bodily pain and discomfort is most important when assessing woman's depressive symptoms regardless of the period of treatment or remission.

- **Depression in the re-entry- or remission phase**

There are a substantial number of breast cancer patients reporting a late increase in distress and psychological suffering in the re-entry and remission phase (20% - 30%) (American Cancer Society, 2010; Burgess et al., 2005; Henselmans et al., 2010). One of the reasons for this occurrence is the sudden end of the visits to the oncologist and other clinical specialists which can leave a person with a feeling of loss to the ready access of the health care system and the safety net it provides. This sense of loss may lead to feelings of vulnerability and of not being in control. Another reason for end of treatment distress, is not knowing what to expect after the end of treatment, what kind of follow-up is typical and which symptoms are important to monitor (Ganz et al., 2004; Golden-Kreutz et al., 2005; Stanton, 2012). Symptoms of depression and emotional distress can cause a contradictory response for survivors who may feel both relieved at having completed treatment and heightened anxiety about the future (Ganz et al., 2004). Evidence from various studies have shown that there are prominent problems related with the transition from being a cancer patient to being a cancer survivor, or returning from a 'cancer patient' back to a 'normal person' (Dolbeault et al., 2009; Henselmans et al., 2010; Stanton et al., 2005). Stanton (2012) states that there are not always effective preparation for the re-entry phase by the health care professionals, leaving the cancer survivors in a stage of 'limbo', therefore it is recommended that all cancer patients undergo regular psychological assessment at key points from diagnosis throughout the treatment process and have access to psychological support (Cook, Salmon, Dunn, Holcombe, Cornford, & Fisher, 2015).

The re-entry phase brings its own particular challenges for the breast cancer patient. The most mentioned problems in this phase are the lingering adverse physical and psychological side-effects of the cancer treatments such as; loss of physical stamina and fatigue, pain, sleep disturbance, cognitive problems, alopecia, urinary/bowel problems, menopausal symptoms and often sexual dysfunctions (Ganz et al., 2004; Golden-Kreutz et al., 2005). Breast cancer survivors often report that they were unprepared for the complex rehabilitation process and persistent symptoms of depression or anxiety after the end of their treatment (Brem & Kumar, 2011; Burgess et al., 2005; Dolbeault et al., 2009; Reyes-Gibby et al., 2012). In a study done by Ganz and co-workers (2004) 16 of their 18 breast cancer patients were astonished and disappointed in themselves to

still experience chemotherapy-related and mood problems months after ending their treatment, especially when they felt that they have coped well during treatment (Brem & Kumar, 2011; Burgess et al., 2005; Dolbeault et al., 2009; Reyes-Gibby et al., 2012).

Apart from the above mentioned problems, other challenges that breast cancer survivors face during this transition phase may include worries about the threat of death, the risk and fear of recurrence, bodily changes with accompanied feelings of decreased femininity, changing psycho-social needs and the uncertainty about the future, especially about relationships and occupational difficulties and financial stress (Ganz et al., 2004; Haber et al., 1995). Most breast cancer survivors experience significant (longer term) fears and even panic about non-cancerous symptoms such as pain, fever, headaches and other somatic symptoms (Haber et al., 1995). This constant fear and worries has the potential to maintain (at least) a low level depression in the post treatment women. Such cognitive and behavioural experiences may greatly interrupt established routines and behaviours that historically have elicited environmental reward or pleasure, the result being a bigger possibility of depression and anxiety (Ganz et al., 2004). Apart from experiencing these residual physical and/or psychological consequences of the cancer treatment, post treatment cancer survivors or patients may realise now for the first time the chronicity of cancer, even when treatment was declared successful (Ganz et al., 2004; Haber et al., 1995).

Added distress in the re-entry phase might be due to a delayed psychological response to the hectic and busy period of diagnosis and treatment. Once in a calmer period, the cancer experience might finally start to sink in for some patients, causing a delayed increase in distress (Henselmans et al., 2010). Because of the immediacy created by the cancer diagnosis (the need for surgery and/or adjuvant treatments) it may delay the emotional experience surrounding other life events. It remains unclear whether the chronic high levels of distress were the result of difficulties in adjusting to cancer or of previous psychological problems, either triggered by or entirely unrelated to cancer. Future research should examine the possible predictors of high distress during the re-entry and remission phase in more detail (Golden-Kreutz et al., 2005; Henselmans et al.,

2010). Studies have suggested that breast cancer survivors are in their highest need of interpersonal support after completing their treatment but often find it unavailable. Family members and friends may expect that, after completion of the cancer treatment, the woman will be able to recommence all of her usual activities and responsibilities at her pre-cancer level of functioning. Psycho-social problems associated with the end of treatment may be compounded by a withdrawal of and changes in the social support system (Ganz et al., 2004; Stanton, 2012; Wurtzen, 2013).

To summarise, the occurrence of a substantial number of breast cancer patients with elevated depression and anxiety well into their remission phase, indicates that breast cancer patients should routinely be screened for psychological distress. This should be done even after the completion of treatments so that the problems can be targeted for preventive and intervention efforts. Helping cancer patients understand what to expect at the completion of medical treatments and how to deal with anticipated problems effectively are critical components of psychological care (Reyes-Gibby *et al.*, 2012; Stanton, 2012; Vahdaninia et al., 2010).

- **Depression and young age**

Breast cancer is diagnosed across a broad age group from teen years through to old age. According to statistics done by Fiszer and colleagues (2014) the average age for breast cancer is 61 years and represents 70% (evenly dispersed) between the ages of 45 and 74. Breast cancer patients younger than 40 years represent between 6% to 7% of all breast cancer patients, with 2.4% younger than 35 years and 0.65% - 1% younger than 30 (Gnerlich, Deshpande, Jeffe, Sweet, White, & Margenthaler, 2009; Hussein et al., 2013; Meier, 2010; Raque-Bogdan, Hoffman, Ginter, Piontkowski, Schexnayder, & White, 2015).

Although a diagnosis of breast cancer is distressing at any age, this occurrence in young women is laden with several unique challenges. Usually, breast cancer occurring in a younger host is differentiated by a more aggressive phenotype and has disproportionately high rates of second malignancies. Previous studies have shown that breast cancer in a younger population is often presenting more aggressively with higher mortality and recurrence rates compared with older

women (Anders, Johnson, Litton, Phillips, & Bleyer, 2009; Gnerlich et al., 2009; Hussein et al., 2013; Raque-Bogdan et al., 2015). Local recurrence in patients younger than 45 years of age was discovered to be four times higher than in patients older than 65 years of age. Clinically, younger women are more likely to present with a palpable mass, larger tumour sizes, more invasive cancers, and more positive lymph nodes than older breast cancer patients which entails more aggressive treatment modalities and the need for closer monitoring and follow-up after-care. Death rates in the breast cancer population have been steadily decreasing, especially in younger women, due to the improved treatment modalities and early detection. Although the diagnosis of breast cancer is much less common in women under the age of 40 years, it can have a greater impact than in older counterparts as it tends to present at a later stage, is more aggressive and has a poorer prognosis (Gnerlich et al., 2009; Hussein et al., 2013).

Chemotherapy, endocrine- and local therapies have the capacity to meaningfully affect young women. This includes physiologic health, future fertility, premature menopause, and bone health and psychological health including changes to the self-image and femininity as they face a diagnosis of breast cancer (Anders et al., 2009; Travado & Reis, 2013). Young woman undergoing chemotherapy for breast cancer may struggle with fertility and pregnancy issues, where most of them had expectations of having more time to be productive (Corney & Swinglehurst, 2014; Gabriel & Domchek, 2010). Although guidelines are available, many women were not given sufficient information or even offered treatments or interventions to preserve their fertility. Means of increasing awareness and understanding of fertility issues are necessary for both the health professionals and for the young breast cancer patient. Different methods of refining the infertility problem need to be evaluated and tested so that these needs of young breast cancer patients can be met in a more effective way (Corney & Swinglehurst, 2014). Chemo-induced amenorrhea also has an impact on bone density (decreasing) compared to women who retain their menstrual function after treatment (Gabriel & Domchek, 2010). All of these factors can then contribute to the developing of a depressive mood disorder in this young population. Lebel and co-workers (2013) described the fear of cancer recurrence as the most frequently cited psychological side-effect of



young breast cancer patients. The fear of cancer recurrence has been described as “the sword of Damocles” that hangs over young breast cancer patients heads for the rest of their lives. Fear of cancer recurrence is defined as fear or worry that the cancer will reappear (grow) in the same organ or in another part of the body.

Compared to older women, young women have more difficulty in adapting to a breast cancer diagnosis. They report more symptoms of distress and worry and have a lower quality of life. More psychological consequences are evident in young breast cancer patients because they tend to have more family and work responsibilities and are more likely to report that their illness and treatment interfere with important roles and activities than is the case in older women (Lebel, Beattie, Ares, & Bielajew, 2013). Due to their roles as mothers, wives and job holders and the demands and responsibilities required by their families and careers, younger women are more prone to experience unhappiness and greater demand for social support when diagnosed with breast cancer. Having young children at home is a stressor for a young mother because the role of caregiver requires a lot of energy and attention that has to compete with the time consuming and energy sapping cancer treatments (Lebel et al., 2013; Wong-Kim & Bloom, 2005). There is evidence that having dependent children (under the age of 18) living at home, increases stress and worries and contributes to fear of recurrence and dying and leaving their young children behind. Younger women, under the age of 35, have constantly been shown to perform worse on a broad range of quality of life domains compared with older women and report greater levels of fear of cancer recurrence (Lebel et al., 2013; Rauch and Muriel, 2004).

A women’s development up to the age of 40 years, which is the age criteria used by community cancer organizations to define a patient as a young cancer survivor, represents a phase of life in which women begin to see themselves as more independent, build their own networks of social support; start their career paths; develop new friendships and romantic relationships; and make important decisions about their identities, careers, and relationships. Having breast cancer during such an important developmental period can impede young women’s ability to adapt to critical life events and have significant implications for the rest of their life path (Maya & Bauer-Wu, 2009; Raque-Bogdan et al., 2015). Despite early-stage

diagnosis and the beginning phases of adulthood, young breast cancer patients anticipate their mortality and the potential implications on their loved ones and their own careers. Maya and Bauer-Wu (2009) suggest that oncology professionals need to be considerate and sensitive to these concerns and provide opportunities for discussion and/or referrals for their young patients as they deal with such potentially overpowering issues.

Career and work concerns may be an important element of post treatment quality of life for young cancer survivors who may have at least 25 or more years left in the workforce. For breast cancer survivors in particular, the decision to work can be affected by anxiety about their physical appearance, e.g. hair loss, physical restraints such as limited arm or shoulder mobility, chemo-induced cognitive impairment and chemo fog and the subsequent impact on their confidence in carrying out daily tasks including work tasks (Munir, Burrows, Yarker, Kalawsky, & Bains, 2010). There is also the possibility of a potential job loss due to the demands of the medical treatment and/or on-going treatment side effects. Raque-Bogdan and co-workers (2015) state that with women between 25–35 years, their career choices are a means of achieving job satisfaction and accomplishment and symbolize ways of personal fulfilment and life satisfaction. According to Raque-Bogdan and co-workers (2015) career troubles take on special importance for breast cancer survivors because a career can function as a sign of quality of life. Functioning properly in your job represents normality and routine after the illness and treatment and symbolises hope for the future and provide access to social support, medical insurance and financial resources.

Young women who had a mastectomy often report feeling incomplete and depressed about the loss of their breast and are more at risk for psychological distress and reported more sexual problems secondary to the breast cancer diagnosis (Wong-Kim & Bloom, 2005). In their study they found that younger women who had higher levels of pain, lower levels of self-esteem and emotional support and severe treatment side-effects were most at risk for experiencing depressive symptoms than older women with breast cancer. A higher percentage rate of young women, under the age of 50, as defined by Wong-Kim and Bloom (2005) met the criteria for being depressed when diagnosed with late stage

cancer. These authors confirm that because of their heightened vulnerability to stress and fear of recurrence, young breast cancer patients are most in need of screening for psychological stress and fear and interventions to help them manage these fears (Lebel et al., 2013; Wong-Kim & Bloom, 2005). The findings of this study indicate that age continues to be an important variable in predicting depressive symptoms.

Raque-Bogdan and co-workers (2015) feel that additional research is needed on unique aspects of young breast cancer survivors' psychological functioning given that young survivors represent a significant percentage of the breast cancer survivor population and that breast cancer in young women remains a great challenge to patients, families and health care providers. Since breast cancer is normally a disease of older women, the majority of breast cancer studies have concentrated on older women and few studies have focused on age as the primary exposure (Gnerlich et al., 2009).

- **Depression and end of life**

Diagnosing and treating depression in terminally ill patients implicate unique challenges. Feelings of helplessness, worthlessness, guilt and sometimes suicidal ideation are better indicators of depression in this population (Block, 2000). The results of a study done by this author, found that depressed patients were four times more likely to have a desire for a hastened death or a wish to die. Hopelessness appears to be an essential element of desire for hastened death. A terminal illness like cancer is by definition incurable and many people might confuse a "hopeless" prognosis with a "hopeless" cognitive style. According to Block (2000) data suggest that patients often maintain hope during the final weeks of their life, although what they hope for might change as death nears.

As death approaches, it is normal for patients with a terminal illness to undergo an expansion in the number and severity of their physical and psycho-social stressors. These stressors can include severe fatigue and growing weakness with incapacitating physical symptoms, loss of independence, decreased social interactions, increased existential distress, death-anxiety and anticipatory (preparatory) grief (Berger et al., 2015). It is important to understand the

epidemiology of psychiatric morbidity among advanced cancer patients to minimize the occurrence of clinicians neglecting cases that justify attention. Existential distress at the end of life is often regarded as natural which may result in clinicians underestimating psychological symptoms, including severe depression (Lichtenthal et al., 2009).

I often found in my practise that, at the end of a patients' life, there is a natural progression of death acceptance (which is supported by authors such as Lichtenthal and co-workers (2009) and peaceful awareness as death approached, but that the immediate family, especially if they were also the main care takers of the patient, often present with depression and can benefit from therapeutic input.

#### **2.2.5.2.2 General anxiety disorder**

Anxiety is one of the most dominant psychological challenges associated with cancer and research conducted in the USA and the UK has shown that anxiety prevails throughout the spectrum of treatment and recovery for female patients with breast cancer, even among the disease-free breast cancer survivors (Montel, 2010; Lim et al., 2011).

- **Diagnostic criteria according to DSM-5R**

The diagnostic criteria of a General Anxiety Disorder according to the DSM-5R are:

- A) Excessive anxiety and worry (apprehensive expectation), occurring more days than not for at least 6 months about a number of events or activities such as work or school performance.
- B) The individual finds it difficult to control the worry.
- C) The anxiety and worry are associated with three or more of the following six symptoms (with at least some symptoms having been present for more days than not for the past 6 months):
  - (a) Restlessness or feeling keyed up or on edge.
  - (b) Being easily fatigued.

- (c) Difficulty concentrating or mind going blank.
  - (d) Irritability.
  - (e) Muscle tension.
  - (f) Sleep disturbance.
- D) The anxiety, worry or physical symptoms cause clinically significant distress or impairment in social, occupational or other important areas of functioning.
- E) The disturbance is not attributable to physiological effects of a substance, or other medical condition (e.g. hyperthyroidism).
- F) The disturbance is not better explained by another mental disorder.

The diagnostic features of a generalized anxiety disorder are excessive anxiety and worry about a number of events or activities. The intensity, duration or frequency of the anxiety and worry is out of proportion to the actual likelihood or impact of the anticipated event. Associated features supporting diagnosis are: Muscle tension, trembling, twitching, feeling shaky and muscle aches or soreness. Somatic symptoms include sweating, nausea, diarrhoea and an exaggerated startle response and hyper-arousal symptoms such as accelerated heart rate, shortness of breath and dizziness, but less prominent than in a panic disorder (American Psychiatric Association (2001). The International Classification of Diseases, Tenth Revision, Clinical Modification (ICD 10 – CM) is used in conjunction with the diagnostic criteria of the DSM-5R for General anxiety disorder which is F41.1.

General anxiety disorder is characterized by persistent, excessive and unrealistic worry about everyday issues. People with this disorder feel that worrying is beyond their control and that they feel powerless to stop it. They often expect the worst, even when there is no apparent reason for concern. Exaggerated and unrelenting worry often centres on issues of health, family, money or work and it can interfere with all aspects of a person's life. Cancer patients with a general anxiety disorder may, during the active phase of cancer, irrationally fear that no one will care for them though they have adequate and a willing social support

system, or that the outcome of the illness will be fatal, despite optimism of the physicians (Montel, 2010).

The most frequent co-morbid psychological conditions are depression and anxiety (Brem & Kumar, 2011; Spiegel & Rodrigues, 2008). In a study done by Mello and colleagues (2013) 44% of the breast cancer survivors reported either depression or anxiety, but only 23.8% discussed these symptoms with their physicians. Gandubert and colleagues (2009) found that 10.4% of cancer patients present with a general anxiety disorder and that re-emerging of the symptoms was as high as 67%. According to Van Oers and Schlebusch (2013) anxiety is the more common disorder between depression and anxiety in the breast cancer population and prolonged anxiety has immunosuppressive effects that can also lead to cognitive dysfunction. This was confirmed in a study done by Lueboonthavatchai (2007) where the results showed a slightly higher incidence in general anxiety (49%) as opposed to depression (46%). Regarding clinical factors associated with anxiety and/or depression disorders in the breast cancer population are: a) the number of hospital admissions, b) existence of disturbing symptoms, e.g. pain, respiratory symptoms and fatigue, and c) the presence of treatment complications. The most common somatic symptoms found in cancer patients were; pain, fatigue and tiredness, insomnia, lack of appetite, weakness and reduced energy and can all be seen as predictors of anxiety and depression. All of these somatic symptoms, which are overlapping each other, complicate the diagnosis of anxiety and/or depression which further complicate the treatment and outcome of cancer (Lueboonthavatchai, 2007).

The diagnosis of a life-threatening illness like breast cancer can be overwhelming and shocking to patients and their families. Confrontation with a person's own mortality can cause acute psychological stress and feelings of anxiety after a cancer diagnosis is not necessarily abnormal, for the threat of cancer is to some degree a realistic threat, but without proper management can become pathological. A significant percentage of breast cancer patients will suffer sufficient emotional stress to qualify for a psychiatric diagnosis, especially depression or anxiety. Apart from the heavy physiological toll on the breast cancer patient, the cancer diagnosis can also create a series of psychological stressors disrupting the

social, occupational and family functioning. It was also reported that anxiety in breast cancer has a detrimental effect on the quality of life of female patients, affecting their physical, medical and sexual quality of life (Brem & Kumar, 2011; Dolbeault et al., 2009; Lim et al., 2011; Spiegel & Rodrigues, 2008). Both chemotherapy and radiation are associated with anxiety and are often the highest before the first application, where anticipation fear for follow-up examinations and their results are also related to high levels of anxiety (Berger et al., 2015; Travado & Reis, 2013; Van Oers & Schlebusch, 2013; Vahdaninia et al., 2010).

- **Health anxiety**

According to Jones and co-workers (2014) there is another (newer) form of anxiety called health anxiety. Health anxiety is defined as a persistent fear of illness or disease that often includes the misinterpretation of physical symptoms as signs of a serious illness. Health anxiety involves contemplating about having or developing an illness or having an existing illness worsen, obsessed with bodily sensations with accompanied behaviours such as seeking medical reassurance or attention. Severe expressions of health anxiety were often classified as hypochondriasis in the *DSM-IV-TR* (Asmundson, Abramowitz, Richter, & Whedon, 2010; Brennen, 2011).

Health anxiety affects a considerable percentage of women following the diagnosis of breast cancer (Asmundson, et al., 2010; Brennen, 2011). While a certain level of health anxiety may be adaptive, (e.g. to alert the patient to watch for signs of recurrence), clinically raised health anxiety can lead women to continuously monitor their bodies all the time and interpret any symptoms as threatening. Severe health anxiety has significant adverse impacts on well-being, social and occupational functioning, and health care resource utilization (Asmundson et al., 2010; Jones, Hadjistavropoulos, & Gullickson, 2014). It is evident that health anxiety is a significant problem for more than 20% of women who have been diagnosed with breast cancer and may present challenges over and above that of the general anxiety experienced as a result of having breast cancer (Jones et al., 2014; Kyranou et al., 2014).

The diagnosis of depression or anxiety in isolation can be challenging because the symptoms of the two conditions often coincide. According to Van Oers and Schlebusch (2013) literature on anxiety as a co-morbid feature is relatively limited although there is evidence that anxiety presented itself in a higher percentage as depression in the oncology population. Van Oers and Schlebusch (2013) claim that breast cancer patients often experience anxiety before the start of treatment, where depression only develops post-treatment. Anxiety also relates more with future concerns such as treatment outcomes and recurrence (Kyranou et al., 2014; Lebel et al., 2013).

Although anxiety levels vary over the course of the cancer treatment, it tends to be the highest during time of diagnoses, before breast surgery and toward the end of treatment in anticipation of the results (Van Oers & Schlebusch, 2013). A recent study done by Aviado-Langer (2014) emphasises that the pre-operative stage was dominated by stressors such as waiting for the surgery and pathology results, fear of the disease and stage. Results of a recent study done by Aviado-Langer (2014) found that patients scheduled for breast-conserving surgery had lower scores for anxiety compared to patients scheduled for a mastectomy. The most common response to a mastectomy appears to be anxiety, possibly in relation to pain, disfigurement and body image (Kyranou et al., 2014; Van Oers and Schlebusch, 2013). In the light that a breast cancer diagnosis is a stressor, it is important to implement preoperative encounters to identify, evaluate, and manage patients' anxieties. Unaddressed, preoperative anxiety may provoke a physiologic stress response in the postoperative progression that can comprise heightened anxiety and postoperative pain, delayed immune response, increased pulmonary risks and thrombus formation (Aviado-Langer, 2014).

Lim and colleagues (2011) have found evidence that concluded that anxiety is a prominent concern enveloping the three main treatment modalities namely, surgery, chemotherapy and radiotherapy. Despite similarities, each treatment modality contributed to anxiety in different aspects. The evidence that these authors gathered disclosed that more than one form of anxiety can co-exist during chemotherapy. One example is acute anxiety, with the intensity measured to be the highest before the beginning of the first dose of chemotherapy. Anticipation



anxiety is another form of anxiety where the patient anticipates the side-effects of the chemotherapy. Cancer patients who anticipate more negative effects from chemotherapy consequently experience a higher level of anxiety. When measuring the effect of radiotherapy on the anxiety level, Lim and colleagues (2011) found that radiotherapy did not seem to affect breast cancer patients' general level of everyday anxiety. In view of the detrimental effects of anxiety and the growing number of female patients with breast cancer, the need to address the issue of anxiety among these patients is warranted (Lim et al., 2011). Findings in a study done by Hill and co-workers (2010) highlighted the vulnerability of women with former episodes of depression and anxiety to develop further mental health issues during the year after diagnosis of breast cancer.

#### **2.2.5.2.3 Post traumatic stress disorder (PTSD)**

According to the DSM-5 (2013) PTSD is categorised as exposure to actual or threatened death, serious injury or sexual violence, directly experiencing the traumatic events. Symptoms associated with PTSD are recurrent, involuntary and intrusive distressing memories, flashbacks and/or dreams of the traumatic event. It also includes intense or prolonged psychological distress at exposure to internal or external cues that symbolise an aspect of the traumatic event or avoidance of stimuli associated with it. The duration of the disturbance must be more than a month and must cause clinically significant impairment in social, occupation or other important areas of functioning.

Psychological trauma is caused by occurrences or experiences which are sudden and unexpected in which the person perceives a dramatic loss of personal control and personal safety. This definition has clear resonance with the experience of cancer where the patient is indeed being confronted with the implications of a life-threatening illness and is included in the DSM-IV as a possible traumatic stressor and the cause of posttraumatic stress symptoms (Ang, 2011; Brennen, 2001). The cancer experience is adequately traumatic to induce PTSD in a minority of cancer survivors. Post-hoc analyses suggest that cancer patients, who are younger, diagnosed with more advanced breast cancer and recently completed treatment may be at greater risk of PTSD, but more research is needed to investigate vulnerability factors for PTSD in cancer survivors (Abbey, Thompson,

Hickish, & Heathcote, 2015). The diagnosis and treatment of cancer may lead to a persistence of such symptoms, without leading to the full syndrome of post-traumatic stress disorder (Brennen, 2001; Dolbeault, 2009). Recently, cancer has been regarded as a traumatic event and DSM-IV has conceived life threatening illnesses as stressors that could elicit a post-traumatic stress disorder (Ruini & Albieri, 2013). Post-traumatic stress disorder has been progressively diagnosed as an additional morbidity among cancer patients. A study done by Mehnert and Koch (2007) has disclosed that the prevalence of cancer-related PTSD ranged from 0% to 32% and literature indicates that a high number of patients, up to 80%, are likely to encounter individual PTSD symptoms following cancer (Brennen, 2001; Dolbeault, 2009; Mehnert & Koch, 2007; Ruini & Albieri, 2013). Breast cancer patients recurrently report future orientated fears, but seldom flashbacks and potential arousal symptoms might interfere with cancer- or treatment-related somatic symptoms, such as sleep disturbance or irritability (Mehnert & Koch, 2007). Post-traumatic stress symptoms were associated with depression, anxiety, distress and physical quality of life (Shand, Cowlshaw, Brooker, Burney, & Ricciardelli, 2015). In contrast to some literature (Brennen, 2001; Dolbeault, 2009; Mehnert & Koch, 2007; Ruini & Albieri, 2013) the DSM-5 states that a life threatening illness of debilitating medical condition is not necessarily considered a traumatic event.

It is sufficient for the benefit of this study to describe and define the three lead psychiatric disorders that correlate with breast cancer and breast cancer treatment: Major Depression, General Anxiety and Post Traumatic Stress Disorder. Although a breast cancer patient can present with other mood disorders in different degrees of seriousness, the above mentioned disorders are the most challenging in terms of diagnosis and treatment for the patient as well as the oncology team.

#### **2.2.5.2.4 Cancer and sexuality**

All current cancer treatments for breast cancer can cause changes in the female body that abruptly affects sexual desire, sexual functioning and emotional relationships (Fobair & Spiegel, 2009; Kaplan, 1992; Sbitti et al., 2011). In spite of these sexual impairments caused by cancer treatments, it has been largely

neglected by oncology teams (Kaplan, 1992). It is important for health care professionals to be conscious of problems related to sexual intimacy and sexual functioning during cancer and cancer treatment and to be prepared to offer information about these aspects and also reflect on their patient's expectations versus the reality (Fallbjork, Birgit, Rasmussen, Karlsson & Salander, 2013).

- **Sex and sexuality**

Sex and sexuality is an integral part of normal life for most individuals and is an important aspect of quality of life. Sexuality can be defined as a personal expression of how a person feels about herself and her body and her relationship with her partner and is in essence central to a person's sense of wellness and self-concept (Sheppard & Ely, 2008). Sexuality is not a concept that can be regarded as separated from that of health and is interrelated with a woman's need for caring, touch, intimacy and communication of sexual needs and the capability to engage in satisfying sexual activities. Attitudes about sexuality affect a woman's enthusiasm and passion for living, self-image and relationship with others (Sbitti et al., 2011). In contrast with sexuality, sexual functioning (sex) refers to the sexual act or activity that is also known as intercourse that implicates functioning such as vaginal lubrication, breast sensitivity and penetration (Cancer Society, 2013).

Research has documented an array of physical changes to a woman's sexuality after breast cancer including disturbances to sexual functioning, disruptions to sexual arousal, lubrication, orgasm, sexual desire and sexual pleasure. These can all be side-effects of chemotherapy, chemically induced menopause, Tamoxifen and breast cancer surgery (Emilee et al., 2010; Hummel et al., 2015; Kuo et al., 2008; Reese et al., 2010). These research results were confirmed by Sbitti and colleagues (2011) where they found that although changes in the breast may not necessarily restrict a women's physical ability to have sexual intercourse, it is greatly associated with sexual well-being, body image and feminine identification. In their study the participants reported worse sexual functioning during cancer treatment, characterized by greater lack of sexual interest, inability to relax and enjoy sex, difficulty becoming aroused, and reaching an orgasm. Sexuality can be affected either emotionally through related stress, anxiety or depression, or through biological changes due to treatment side-effects.

- **Hormones and sex**

The hormones that contribute to sexual desire are termed oestrogen and androgen. Oestrogen is a female steroid hormone that is produced by the ovaries and helps control and guide sexual development. Oestrogen is the major hormone in sexual functioning, playing a vital role in arousal, peripheral sexual response and pelvic sexual response (Kuo et al., 2008). Oestrogen deficiency can lead to lack of menstruation (amenorrhea), vaginal dryness, pain during vaginal penetration and dyspareunia, menopause and osteoporosis in older age. Oestrogen helps keep the vagina moist and flexible and facilitates change when sexually aroused. During the process of arousal the vagina gets longer and wider and the cells lining the vagina produce and discharge droplets of fluid that makes the vagina moist. Without oestrogen the vaginal lining thins, its walls lose some of their ability to stretch and will stay tight and dry even when sexually excited, which is called vaginal atrophy (American Cancer Society, 2013; Derzko, Elliott, & Lam, 2007).

Androgens are called "male hormones," and although it is the male sex hormone, it is also natural to the female body and is produced in the ovaries, adrenal glands and other tissues. Androgens plays a key role in the prevention of bone loss, as well as sexual desire and satisfaction and low androgen levels in women are linked to decreased sexual desire (low libido), genital sensation and genital response that can cause lethargy and loss of sexual interest (American Cancer Society, 2013; Derzko et al., 2007).

- **Sexual response cycle for woman**

Nusbaum and colleagues (2003) categorize sexual response into five stages: desire, arousal, plateau, orgasm and resolution that are schooled on the stages of sexual response of Masters and Johnson (1966) and Kaplan (1979).

- Desire - The first phase of the sexual response cycle involves generating a desire and includes physiologic factors such as neurotransmitters, androgens and the sensory system and a wide variety of environmental stimuli, such as psychosocial and cultural factors. Desire causes a person

to initiate or be receptive to sexual activity (Georgiadis & Kringelbach, 2012; Nusbaum et al., 2003).

- Arousal - involves the parasympathetic nervous system and vascular system e.g. breathing becomes heavier, heart rate and blood pressure increase and reflective vasocongestion occurs which includes vaginal lubrication and enlargement of the clitoris (Nusbaum et al., 2003).
- Plateau - includes the parasympathetic nervous system and vascular system. Vasocongestion phase (vasocongestion refers to the swelling of genital tissues with blood) is at its peak where sexual tension increases and then levels off immediately before orgasms with carpo-pedal spasms, generalized skeletal muscular tension, hyperventilation, tachycardia and increased blood pressure (Nusbaum et al., 2003).
- Orgasm - includes the sympathetic nervous system and muscle tone. It will cause heightened excitement to a peaking of subjective pleasure followed by release of sexual tension, pelvic response consists of involuntary contractions and myotonia (tension may be seen in the neck and face, buttocks, thighs), carpopedal spasms, contractions of arms and legs, external rectal sphincter contractions, external urethral sphincter contractions, hyperventilation, tachycardia and increased blood pressure (Georgiadis & Kringelbach, 2012; Nusbaum et al., 2003).
- Resolution - involves the sympathetic nervous system. The body now returns to pre-excitement phase as vasocongestion is relieved and hyperventilation and tachycardia decrease. (Nusbaum et al., 2003).

- **Female sexual dysfunction**

The Female sexual dysfunction is multi-factorial and refers to a lack of healthy and normal sexual response and interest. Contributing factors of this dysfunction can be psychological, biological, interpersonal or contextual (Bredart et al., 2011; Derzko et al., 2007). Sexual functioning is progressively understood as a truly bio-psycho-social phenomenon. A healthy sexual response depends on the neurologic, vascular and endocrine systems and is influenced by numerous psycho-social factors including certain personal and interpersonal factors. It is subject to modifications by illness, disability and the aging process itself. Because

of the multifaceted nature of sexual dysfunctions, collaboration and cooperation between all health care providers (multi-disciplinary team) is essential to ensure that the patient's quality of life remains as important as her prognosis (Hughes, Hertlein, & Hagey, 2011; Kuo et al., 2008; Nusbaum et al., 2003; Speer et al., 2005).

Sexual dysfunction is a complex disorder which is a subject that requires thorough exploration to understand its etiology. According to Dean (2008) human sexuality has both physical and emotional elements which can be difficult to separate. Sexual dysfunction can either represent a primary physiological or psychological disorder (e.g. depression) or a secondary disturbance associated with the presence of a general medical condition (cancer) or the use of a substance or medication (psychotropic medications) (Krychman & Katz, 2012; Rivas-Vazquez, Blais, Rey, & Rivas-Vazquez, 2000). Dean (2008) used the example of a low libido which could be caused both by a physical change in menopausal status and an emotional change in mood. Sexual problems caused by the diagnosis and treatment of breast cancer can be a complex side effect to manage.

A breast cancer patient may become disinterested in sex and become sexually inactive during her treatment or at least for some time during her treatment. Immediately after a cancer diagnosis, anxiety and worry about survival is so immense and issues of mortality all consuming, that sex is not necessarily an immediate priority. This is a normal reaction and state of mind, but once a woman gets back to her normal routines, her interest in sex may return (American Cancer Society, 2010; Katz, 2005; Taylor, Harley, Ziegler, Brown, & Velikova, 2011). Bearing this in mind, Reece and colleagues (2010) underline the fact that even during treatments such as chemotherapy and hormonal therapy, the patient and her partner can still have intimacy and sexual needs and that maintaining sexual activity can be a sign of overall wellbeing as well as the ability to cope with the cancer and its treatment.

Apart from the possibility to develop a mood disorder it is widely recognised that breast cancer has a direct effect on sexual functioning and many women experience sexual problems as a result of breast cancer and cancer treatment. The impact of these changes can last for many years after successful treatment

and can be associated with critical physical and emotional effects (Emilee et al., 2010; Katz, 2005; Reese et al., 2010; Taylor et al., 2011). In more recent studies a relatively large percentage of the breast cancer participants (between 30% and 100%) have presented with sexual complaints and dysfunction as a consequence of their disease and its treatment (Hummel et al., 2015; Kuo et al., 2008; Murray, 2010; Park et al., 2009). In a study done by Bredart and colleagues (2011) a substantial number of breast cancer survivors have experienced sexual problems, especially a decrease in libido, dyspareunia and an inability to achieve orgasm in the period between six months and five years after completion of treatment. Contrary to that finding, Fobair and co-workers (2006) have found that especially in the first year after diagnosis, body-image problems and sexuality were at its worse. Where levels of emotional distress tend to be higher in the first few months after a cancer diagnosis, especially the fear of death, sexual problems on the other hand has been shown to worsen beyond the first year after diagnosis and breast surgery, indicating that maladaptive patterns concerning body image and sexuality are inclined to enhance with time. Because of the seriousness of sexual problems in this cancer population, it justifies early detection and intervention.

Although sexual functioning is an important health issue, there is often a lack of recognition that it is a problem. Because cure and management of the disease are primarily the main targets in the mind of the oncologist, sexual functioning is often neglected and unaddressed. Health care professionals may feel hesitant to ask their breast cancer patient about her sexual functioning during medical consultations due to time limits, embarrassment or lack of knowledge and experience in this area (Kuo et al., 2008; Park et al., 2009; Reece et al., 2010). Cancer patients, on the other hand, may also feel reluctant to raise their sexual issues with their cancer specialist because of the limited opportunity to do so, yet there is evidence that many cancer patients would be keen to discuss issues of their sexuality related to their cancer treatment with their health providers (American Cancer Society, 2013; Hummel et al., 2015; Kuo et al., 2008; Park et al., 2009; Reece et al., 2010). Because of this tendency, Speer and colleagues (2005) feel strongly that psychological sexual assessment should be included in the oncology physicians' standard assessment protocol and treatment. There is a growing recognition regarding the limitations in which sexual concerns are

presently being addressed in the breast cancer population which is now ripe for studies of psycho-social interventions as an addition to pharmacologic treatments (Krychman & Katz, 2012).

The four diagnostic groups within female sexual disorders and the most frequent sexual problems or dysfunctions related to breast cancer and breast cancer treatment are:

- (a) Hypoactive sexual desire disorder,
- (b) Female sexual arousal disorder,
- (c) Sexual pain disorder, and
- (d) Orgasmic disorder (Bredart et al., 2011; Derzko, et al., 2007; Speer et al., 2005).

These disorders can lead to loss of sexual satisfaction, causing disappointment and frustration within the couple which then can lead to reduced sexual activity. General emotional welfare and the quality of the relationship with the partner can be affected by the degree of distress caused within the couple due to a diagnosis of breast cancer. According to Bredart and colleagues (2011) younger couples are more susceptible to relationship tension which consequently can lead to emotional separation (Bredart et al., 2011).

Factors underlying female sexual dysfunction:

- Biological factors, such as aging and menopause, endocrine changes, illness or disability, surgical interventions and some prescription medications can alter a person's sexual functioning. Cancer does not have to involve sexual organs to affect sexual functioning.
- Psychological distresses have a profound effect on sexuality, including psychiatric conditions (e.g. depression or anxiety), sexual confidence influenced by emotions and low self-esteem, performance anxiety, low quality of life, irrational thought patterns, interpersonal conflict and lack of sexual desire (Laumann, Paik, Raymond & Rosen, 1999; Graziottin & Leiblum, 2005).

## **1. Hypoactive sexual desire disorder (HSDD)**



Sexual desire, also referred to as libido (biologically driven urge) implicates fantasies regarding sexual activity and desire to engage in activity (Derzko et al., 2007; Rivas-Vazquez et al., 2000). Absent or low sexual interest is not intrinsically pathological, but may become problematic in the context of inter-partner sexual desire discrepancy (ter Kuile, Both, & van Lankveld, 2010). Hypoactive sexual desire disorder is characterised by an absence or lack of sexual fantasies and desire for sexual activity causing emotional distress or interpersonal difficulties and can be caused by the effects of a psychiatric disorder, e.g. major depression or anxiety, pathology (as in an illness or disease, such as breast cancer) or treatment modalities, including chemotherapy and medication (Kaplan, 1979; Mimoun, 2011).

Symptoms of HSDD are:

- An absent desire before sexual activity.
- Desire is not triggered during sexual experiences.
- Distressed feelings about the problem.

During cancer treatment a lessened sexual desire or lack of libido is a common problem and may be caused by treatment side-effects such as nausea, pain and fatigue, or hormone treatments that can interrupt the normal hormone balance. Disturbing and anxious thoughts can distract a woman from getting aroused, resulting in a tight and dry vagina which can make intercourse painful and difficult. Psychological side-effects of cancer treatment such as anxiety and depression can also affect sexual desire (American Cancer Society, 2010, Mimoun, 2011; Strasser et al., 2006). Low sexual desire can be associated with decreased functioning in other aspects of sexual response and can cause physical and emotional dissatisfaction, disappointment and frustration in a woman's sex life and relationship (Dennerstein, Koochaki, Barton, & Graziottin, 2006; Fobair et al., 2006). Menopausal status is important to sexual desire and sexual arousal. Studies have shown that cancer patients who had surgical and cancer related treatment induced menopause are at a greater risk for decreased sexual desire compared with premenopausal or naturally menopausal women (Graziottin & Leiblum, Koochaki, Rodenberg, Barton, & Rosen, 2006; Dennerstein et al., 2006). Because of the high incidence of depression in breast cancer patients, this is a

population which are often high consumers of anti-depressants that have a direct influence on sexual desire (Basson & Schultz, 2007; Meier, 2010; Reyes-Gibby et al., 2012; Rivas-Vazquez et al., 2000).

## **2. Sexual pain disorders**

Cancer survivors may experience sexual pain disorders that include difficulties allowing vaginal entry called dyspareunia and vaginismus. Dyspareunia is a persistent or recurrent pain during sexual activity that is associated with attempted vaginal entry, or penile vaginal intercourse. Pain is a common result of radiation therapy, menopause or adjuvant treatment that affects a woman's hormones and is often related to changes in the vagina's size or moistness (Murray, 2010; Roland et al., 2010, Ter Kuile, *et al.*, 2010). Sexual pain can set of a problem called vaginismus which is a persistent or recurrent difficulty to allow vaginal entry of a penis, a finger or any object because the muscle around the opening of the vagina become tense despite the women's expressed wish to do so. Vaginismus can become a phobic avoidance in anticipation of pain (American Cancer Society, 2010; Murray, 2010). Pain can lead to avoidance of any form of intimacy and fear of intercourse (Murray, 2010).

## **3. Orgasmic dysfunction**

Orgasmic dysfunction characterizes the inability to achieve an orgasm, markedly diminished intensity of orgasmic sensations, or an obvious delay of orgasm during any kind of sexual stimulation (Lewis et al., 2010; Ter Kuile et al., 2010). Most women are normally able to have orgasms after cancer unless the cancer or treatment has harmed the spinal cord and caused the genital area to be numb. Pain during intercourse, which are often the case with breast cancer patients may be a distracting factor from reaching an orgasm (Lewis et al., 2010). Anti-depressants, especially SSRIs can biologically incapacitate the orgasm stage of sexual functioning (Rivas-Vazquez et al., 2000) and it will benefit the patient to be informed of this side-effect of anti-depressants.

## **4. Sexual arousal disorders**

Arousal is defined as the subjective sense of sexual pleasure and accompanying physiological changes which means major changes consisting of vasocongestion in the pelvis, vaginal lubrication and expansion and swelling of the external genitalia (Rivas-Vazquez et al., 2000). Arousal dysfunction implies absence or impaired genital sexual arousal, which may include minimum swelling or vaginal lubrication from any type of sexual stimulation and reduced sexual sensation from direct stimulation of the genitalia (Lewis et al., 2010). Arousal problems may derive from inadequate physiological support to allow for appropriate vasocongestion, inadequate mental and/or physical sexual stimulation, or disrupting factors such as stress, pain and discomfort which can all be part of the breast cancer patients' experience.

- **Menopause**

Menopause is the time in most women's lives when menstrual periods stop permanently (twelve consecutive months after the last menstrual period) and it also indicates the end of fertility and child bearing years (McKinlay, 1996). The end of the menstruation cycle is a universal experience among human females. It is not an abrupt occurrence, but a gradual process. The average age of natural menopause is 51 years. In Western countries during the past three decades menopause between 40 and 45 years is called early menopause and premature menopause or ovarian failure is defined as a cessation of menstruation before the age of 40. Premature menopause is an occurrence outside the normal life course and as such is likely to have a significant impact on the physical and emotional well-being of women. Premature and early menopause has an increased risk of cardiovascular disease, vasomotor symptoms, vaginal dryness, dyspareunia, weight gain, and osteoporosis (Brem & Kumar, 2011; Deeks, Gibson-Helm, Teede, & Vincent, 2011; Derzko et al., 2007; Ewertz & Jensen, 2011).

For younger breast cancer patients, chemotherapy or ovarian ablation, (ovarian ablation is the medical term for prevention of the ovaries to produce oestrogen, either temporarily or permanently), may cause them to undergo earlier menopause. Symptoms of premature menopause, which is the same as menopause, are: hot flushes, palpitations, less bone density, urinary urgency, and short term memory loss, inability to concentrate, weight gain, mood swings,

reduced libido, painful intercourse and vaginal dryness. Younger women who experience a treatment-induced menopause may also have to cope with feelings around the loss of their fertility, which can affect their relationships both emotionally and sexually (Dean, 2008). Chemotherapy related amenorrhea can be temporary or permanent (Brem & Kumar, 2011).

Cancer treatment can affect a woman's sex life by causing premature and abrupt menopause, leading to reduced sexual desire in some women. When a breast cancer patient's ovaries are removed as part of cancer surgery, or when the ovaries are affected by chemotherapy or radiation to the pelvis, the loss of oestrogen can trigger vaginal changes such as vaginal atrophy (where the vagina becomes tight and dry) and hot flushes. The physical symptoms of premature menopause are likely to be more severe compared to those of women who experience a natural menopause at midlife, and this in turn reduces overall quality of life (Deeks et al., 2011; Meier, 2010; Hummel et al., 2015). Women who have premature menopause can also have low androgen levels, which can be linked to lower sexual desire. As opposed to sudden and unexpected menopause, healthy women who experience age related physiological changes due to low oestrogen, experience the changes gradually over a period of time with more time to adapt to the changes and fewer problems in sexual functioning (Fobair & Spiegel, 2009; Meier, 2010).

Fears and uncertainties that accompany premature menopause are that of weight gain, loss of sexuality and decreased sexual function, infertility and loss of femininity. Premature menopause is also associated with a higher incidence of depression and anxiety, grief and a negative body image (Deeks et al., 2011). Several studies have confirmed that breast cancer patients treated with chemotherapy experience vaginal dryness and early menopause resulting in less sexual activity with their partners. Vaginal dryness, especially, tends to be a physiological disappointment for women suffering from menopause, but is even more so for younger women who are diagnosed with breast cancer during the most sexually active years of their lives (Fobair & Spiegel, 2009; Deeks et al., 2011). A study done by Fobair and Spiegel (2009) has shown that up to 50% of their study patients struggled with sexual problems that did not improve with time. It was also

found that breast cancer patients with premature menopause have reported a lack of information and support in this area from their oncology team (Deeks et al., 2011).

Breast cancer patients of all ages who have hormone-sensitive breast cancer will generally be treated by hormone therapy, which can include Tamoxifen and aromatase inhibitors. These treatments can cause menopausal-type side effects and are largely initiated by oestrogen deficiency (Dean, 2008; Derzko et al., 2007; Ewertz & Jensen, 2011; Hummel et al., 2015).

- **Body image**

In addition to the physical effects experienced as a result of breast cancer, there are prominent psychological affects in the form of body image concerns that can constrain sexual functioning in both partners (Dye, 2008). Body image is defined as the mental picture of one's body, a mind-set about the physical self, appearance and health status, wholeness, normal functioning and sexuality. Body image is an element of a larger concept of self and that for woman means feeling feminine and attractive, enjoying one's body as a symbol of social and sexual expression (Fobair, Steward, Chang, D'Onofrio, Banks, & Bloom, 2006). The way in which a woman experiences her body is highly subjective and is a result of her own observations, thoughts and feelings about her body size, competence and functioning. Fobair and colleagues (2006) have found that a better body image and higher levels of self-confidence results in better coping with breast cancer. According to these authors, negative perceptions of body image amongst breast cancer survivors comprise dissatisfaction and unhappiness with physical appearance, perceived loss of femininity and body integrity, reluctance to look at one naked, feeling sexually unattractive and self-conscious about surgical scars and appearance.

Loss of a breast, surgical scarring, alopecia, weight changes and lymphedema are all sequelae that can impair quality of life in general and body image in particular in women with breast cancer, especially younger women (Katz, 2005; Rosenberg et al., 2012). Alopecia, which ranks among the most feared effects of chemotherapy, is similar to a loss of self or identity (Kuo et al., 2008).

Chemotherapy may also cause weight gain as may the use of hormonal therapies such as Tamoxifen, which can alter the body image even further, leading to negative feelings about their appearance (Dean, 2008).

Nozawa and co-workers (2013) found in their study that there were as many as 80% of their study patients concerned about the alterations in their appearance arising as a result of cancer therapy. These authors have found that the female patients felt greater distress than the male patients with regard to symptoms that affected their appearance and they were more aware of their appearance. It was evident that physical appearance can influence a persons' sense of self. According to Derzko and colleagues (2007) the cancer patients who are the most vulnerable to both body image and sexuality are the patients with advanced breast cancer and in those who need adjuvant treatment, patients who have lymphedema, are inactive, have poor family and social supports, or are single or in an unstable relationship.

Breasts, apart from having a feeding function, are often thought of as a symbol of womanhood and sexual attractiveness and are seen as a source of erotic pleasure and stimulation. The breast is related with a woman's femininity, maternal role, sexuality and intimacy. Breast cancer and cancer treatment, either surgical or adjuvant can result in a traumatic experience due to the loss of femininity, a healthy body, self-image, sexuality or even intimate relationships, especially for younger and sexually active women (Hummel et al., 2015; Kalaitzi, Papadopoulos, Vlasis, Skandalakis, & Pilippou, 2007; Katz, 2005; Lueboonthavatchai, 2007; Sbitti et al., 2013; Taylor et al., 2011). Although some evidence suggests that sexual problems connecting to surgery may improve over time, some patients might still need additional psychological support following surgery to help them adjust. While self-esteem and body image are already affected by breast surgery, it may be further compromised by the development of lymphedema that can occur after axillary surgery or radiotherapy (Dean, 2008).

Some breast cancer patients report a dislike for being touched in the breast area after a mastectomy or lumpectomy because of pain or tenderness. Disfigurement and pain associated with mastectomy and radiation can cause concern about

sexual attractiveness and femininity and affect women's ability to see themselves as sexual beings (Hummel et al., 2015).

Apart from a lumpectomy and mastectomy, which have been associated with changes in sexuality due to significant changes in body image and self-esteem, radiotherapy also includes changes that affect sensitivity of the breast. These changes can result in thickening and scarring of connective tissue (fibrosis), or changes in skin texture and colour, and sometimes even mastalgia (breast pain), any of which can affect a women's perception of herself and desire or ability to enjoy sexual functioning (Kuo et al., 2008). Breast cancer patients who had breast conserving surgery have fewer body image concerns in comparison with breast cancer patients who underwent more radical surgery. It seems that reconstructive surgery appears to alleviate the impact on the sexual body image to some degree, at least for the short-term.

### **2.2.6 Summary**

Interpreting the literature concerning breast cancer, it is conclusive to presume that cancer, specifically breast cancer, and breast cancer treatments, have a devastating effect on the patient and the patient's family. In spite of high-quality progress in the last decade in detecting breast cancer and cancer treatments, especially chemotherapy, the effect of this disease is still traumatic. These traumatic effects can be categorised in the physical, emotional and sexual well-being of the breast cancer patient, with emphasis on mood and sexual dysfunctions. While some of the effects can be temporary, many of the signs and symptoms can last for many years after successful completion of the treatment. Although the diagnosis of breast cancer can occur over a wide variety of age groups, the biggest incidence is after 50 years with the most devastating impact on the younger population. A younger age group is also the breast cancer population where more research is necessary to understand their specific needs. In order to assist and support the breast cancer patient and her family throughout the duration of her illness and even thereafter, it is crucial to identify and understand the psychopathology of breast cancer and its treatment.

## CHAPTER III

### PSYCHO-ONCOLOGY– A THEORETIC OVERVIEW

“The art of oncology is when the tumour is not the target” (Vickers, *et al.*, 2005. p4013).

#### 3.1 INTRODUCTION

In the past, psychological and social issues in cancer were not the subject of scientific inquiry. This lasted until the last two decades where the concept of holism has been the guiding framework for recent recognition of the importance of complete and inclusive cancer care (Nicolas, 2013). In his paper, Miles (2009) wrote that it is often said that, until it is possible for clinicians to always cure or ameliorate (to heal or to make something better) completely, it is their “reasonable responsibility” to offer comfort of genuine human empathy. Such reasoning seems to assume that comforting is a substitute for curing when curing is not possible and that in reality, curing should never be separated from comforting and caring. Otherwise medicine becomes nothing more than the application of technical procedures or the administration of medications outside of the context of the necessarily human encounter.

It is the task of the oncology team, especially the psychological services, to incorporate and treat the human side of the tumour and to be able to accommodate the biological features together with the psychological aspects of the cancer patient. It is imperative that the cancer patient always feel understood and valued as a human being and be treated throughout the whole trajectory of the cancer experience with empathy and dignity (Miles, 2009).

Cancer is the first field of medicine where psycho-social factors have been taken seriously. One of the reasons for considering psycho-social factors was the potency of cytotoxic drugs and the severity and continuity of its adverse effects



both emotionally and biologically on the cancer patient. This chronicity and often permanency of cancer-related side-effects have led to more interest and research in the quality of life of the cancer patient and to balance this with improvements in longevity of life. Cancer, more than any other disease, confronts a person with serious existential issues. It challenges the sense of control over life and raises questions of worthlessness and futility of life as well as what is seen as a good life and a good death (Clarke, 2010). Arising from this, it became impossible to maintain only the biological element of cancer, ignoring the psychological and social elements.

Although the occurrence of distress among cancer patients and serious adverse impact on patient welfare and quality of life had been well documented, it still has not been given the attention it warranted by both medical physicians and advocates for advancements in clinical cancer practise (Breitbart et al., 2013). According to these authors, approximately 40% of cancer patients and family members experience levels of psychological distress that require specific intervention. But of the 28 million people worldwide with cancer (as well as their family members), only a minority of those in need receive suitable psycho-social cancer care by trained professionals. This results in widespread and unnecessary suffering. Because of this worldwide tendency and the rising numbers of cancer survivors, there is an urgent need for further development and implementing of the psychological part of cancer care.

To comprehend the paradigm of psycho-oncology, a theoretical framework was attained from Engel's humanistic or psychological model (caring) and Pasteur's biomedical model (curing). These two models form the basis and approach of this study and the reader needs an understanding of the development of these two models and where the terminology (psycho-oncology) originates from (Borrell-Carrió, Suchman, & Epstein, 2004).

### **3.2 THE BIO-MEDICAL MODEL**

Up to the 70s the bio-medical model was the only accepted scientific model regarding medicine in the world with very little regard for the human side of any disease.

### **3.2.1 History and development of the bio-medical model**

The bio-medical model, that has been the dominant force in western medicine, was largely schooled on Louis Pasteur's (1822-1895) germ theory of diseases. This model proposed that all diseases are a product of a biological defect, initiated by a biologic pathogen. This model is reductionist (reductionism is a procedure or theory that reduces complex data and phenomena to simple terms), seeking to explain all disease in biological terms. It is also exclusionary, since any symptom that cannot be explained in biological terms, are excluded from consideration. This theory has led to mind-body dualism in which mental disorders were often excluded from the primary concerns of medicine unless they could be explained by an underlying somatic defect (Johnson, 2012).

The western bio-medical paradigm has been effective over many centuries in delivering health care because infectious diseases, which were the challenge of the 19th and 20th centuries, accounted for most of the deaths. However, by the end of the 20th century, infectious diseases have given way to the occurrence of chronic disease such as heart disease, diabetes, cancer and strokes and life expectancy had grown from 47 years in 1900 to 77 in 2000 (Borrel-Carrio et al., 2004; McHattie: Cumming & French, 2014). Unfortunately, the bio-medical model has limitations within its paradigm for the social, psychological and behavioural elements of illness and the predominance of this model were beginning to be challenged (McHattie et al., 2014).

Miles (2012) explained the history and development of the bio-medical model into the bio-psycho-social model of health care by concluding that the rapidly accumulating psycho-neuro-immunological and genomic (genetics) research are generating a growing biological and empirical foundation for the functional interrelationship between the somatic, the psyche and the spiritual dimensions of man. According to Miles, medicine that remains fixated with the 'biological body' and which ignores (passively or actively) the status of the non-physical dimensions of the patient which impact the biological function, may therefore be considered incomplete as a true account of the human and his needs. Medicine has the irreversible obligation to care, to comfort and to console as well as to ameliorate, lessen, and cure. It is crucial that these two characteristics care and cure be kept

together and conserved. This must be done in functional integration rather than allowing them to drift apart as if they were polar counterparts or could function in any way as alternatives. The ability to successfully integrate these functions will improve and enhance medicine as a profession. This will not only facilitate care for the patient but also apply technical expertise in attending to the biological dysfunction of the illness. Miles (2012) emphasises that such an approach reconnects the science, humanism and ethics of medicine. It is in the combination of these three components that person-centred medicine is to be found.

New paradigms like holistic-, humanistic- and narrative-evidence-based medicine and medical cosmology has been proposed. This was done continually as a manner to fight modern bio-technological reductionism and to put the person in all his or her dimensions at the centre of the therapeutic encounter (Miles 2009). For this very reason, the bio-psycho-social model of health care practice has been put forward as means of connecting the different disciplinary practice models of mental and physical health and relationships with service users and carers (Ghaemi, 2009; Vetere, 2007).

Yet, in spite of the on-going struggle to integrate the human side with the pure biological side, (cure vs. care), Miles (2012) is quite outspoken in his paper about modern medicine. He feels it still places too much emphasis on the study of organ systems and the use in practice of objectively measurable biological indicators of dysfunction and disease. While, he said, there is no argument against the fundamental importance of such an approach, there is a point where such an emphasis becomes disproportionate in the sense that this so-called objectification of the somatic rejects the human dimension off illness and jeopardies reaching a point where the patient is seen as part of the disease, rather than the disease being seen as part of the patient. Miles said that Western medicine has ventured dangerously close to precisely such a point. He concluded by saying that medical knowledge of illness in purely biological terms without an understanding of the patient as a person, is ipso facto incomplete.

### **3.3 THE BIO-PSYCHO-SOCIAL MODEL**

In response to this challenge, George Engel (1913 to 1999) an American psychiatrist with psychoanalytic training proposed a new medical model during the 70's which offered a holistic alternative to the prevailing bio-medical model, namely the bio-psycho-social model. Unfortunately the U.S. health care remained rooted in the bio-medical model until recently. The aim of this new model was to develop and implement patient-centred care provided by interdisciplinary teams (Borrel-Carrio et al., 2004; Engel, 1989; Epstein, 2004; Ghaemi, 2009; Johnson, 2004). Engel formulated this bio-psycho-social model as a dynamic, interactional, but dualistic interpretation of human experience in which there is mutual influence of body and mind (Borrel-Carrio et al., 2004).

#### **3.3.1 History and development of the bio-psycho-social model**

George Engel formulated the bio-psycho-social model as a dynamic, interactional and dualistic view of human understanding in which there is mutual influence of body and mind. He believed that to understand and respond effectively to patients' distress and to give them a sense of being understood, clinicians must attend simultaneously to the biological, psychological, and social dimensions of illness. He offered a holistic alternative to the prevailing bio-medical model that had dominated industrialized societies since the mid-20th century. His new model came to be known as the bio-psycho-social model and was formulated at a time when science itself was developing from an exclusively analytic, reductionist, and specialised enterprise to become more contextual and cross-disciplinary. Engel did not deny that the conventional bio-medical research had promoted important advances in medicine, but he criticized its extremely narrow bio-medical focus for leading clinicians to regard patients as mere objects ignoring the possibility that the subjective experience of the patient was amenable to scientific study. In developing his bio-psycho-social model, Engel challenged three main components in bio-medical thinking that he believed were responsible for dehumanizing care (Borrel-Carrio et al., 2004; Engel, 1977).

First, he criticized the dualistic nature of the bio-medical model which separates the body and mind only to focus on the disease to the exclusion of the individual who was suffering without connecting the two fields. He indicated a more

integrative view, emphasized the appearance of an illness resulting from the interaction of diverse causal factors, including those at the molecular, individual, and social levels (Borrel-Carrio et al., 2004; Engel, 1977).

Second, Engel criticized the excessively materialistic and reductionist focus of medical thinking. According to these standards, anything that could not be objectively verified and explained at the level of cellular and molecular processes was ignored or devalued. The main focus of this criticism was that psycho-social variables play a more important role in susceptibility, severity and course of illness than were previously appreciated by those who maintain a bio-medical view of illness, leading to a cold, impersonal, technical and bio-medically-oriented style of clinical practice, neglecting the human dimension of suffering (Borrel-Carrio et al., 2004; Engel, 1977).

The third element was the influence of the observer on the observed. Unlike inanimate subjects of scientific scrutiny, patients are profoundly influenced by the way in which they are studied, and the scientists engaged in the study are influenced by their subjects. Engel understood that one cannot apprehend a system from the inside without disturbing it in some way, in other words, in the human dimension, as in the world of particle physics; one cannot accept a stance of pure objectivity. To that concern, Engel provided a rationale for including the human dimension of the physician and the patient as a legitimate focus for scientific study. Engel advocated his ideas not only as a scientific proposal, but as a fundamental ideology that tried to reverse the dehumanization of medicine and disempowerment of patients. His model brought a meaningful and hopeful element to those sectors of the medical profession that wished to bring more empathy and compassion into medical practice (Borrel-Carrio et al., 2004; Engel, 1977).

The bio-psycho-social model is both a philosophy of clinical care and a practical clinical guide. Philosophically, it is a way of understanding how illness, disease and distress are influenced by multiple levels of organization. These levels varied from the social to the molecular where on the practical side it is a way of understanding the patient's subjective experience as an essential contributor to accurate diagnosis, health outcomes, and compassionate care (Borrell-Carrió, et al., 2004; Engel, 1977;).

In an article written by Borrel-Carrio and colleagues (2004) they defended and supported Engel's bio-psycho-social model as a necessary contribution to a scientific clinical method and critically examine and revise three areas in which the bio-psycho-social model was offered as a "new medical paradigm":

- (a) A world view that would include the patient's subjective experience alongside objective bio-medical data.
- (b) A model of connection that would be more comprehensive and naturalistic than simple linear reductionist models.
- (c) A perspective on the patient-clinician relationship that would accord more power to the patient in the clinical process and transform the patient's role from passive object of investigation to the subject and protagonist of the clinical act. This emphasised the need to change the clinician's stance from objective detachment or reflective participation, infusing care with greater warmth and caring.

Patient- and relationship- centred approaches propose that arriving at a correct bio-medical diagnosis is only part of the clinician's task. It insists on interpreting illness and health from an intersubjective standpoint by giving the patient the freedom to articulate his or her concerns, asking about the patient's expectations, and encouraging the health professional to show the patient some humanity. These approaches represent movement toward a more equal relationship in which the clinician is aware of and careful with his or her use of power (Borrel-Carrio et al., 2004; Steward, 2001). In conclusion, Borrel-Carrio and colleagues (2004) state that the value of the bio-psycho-social model has not been in the discovery of new scientific laws (as the term "new paradigm" would suggest) but more in guiding cautious application of medical knowledge to the needs of each patient.

### **3.4 PSYCHO-ONCOLOGY**

#### **3.4.1 Definition and description**

The word oncology comes from the Greek word 'onkos', which means a "mass", "tumour" or "volume" (Barraclough, 1999). Oncology is the study of cancer and is a specialty practise. The field of oncology has three major areas namely medical, surgical and radiation. An oncologist is the medical specialist who treats cancer

and is the main health care provider for a cancer patient. The oncologist also gives supportive care and may coordinate treatment given by other specialists (Spiegel & Rodrigues, 2008). The word psycho comes from the Greek word 'psyche' which means the mind or soul. Psycho-oncology is a relatively new scientific discipline which combines the study of the biological- and psychological aspects associated with cancer and are involved with relationships between cancer and the mind. Psycho-social oncology is a similar term with an even broader implication that cancer concerns not just the individual patient, but their families, friends and colleagues and the society in which they live (Kidman & Edelman, 1997; Barraclough, 1999).

Until the past two decades, psychological and social issues in oncology were never the subject of scientific inquest anywhere in the world, but since then, psycho-oncology as a new field has started to develop. Psycho-oncology recently has achieved subspecialty status with its own body of knowledge contributing to cancer care and operating as a multidisciplinary field involved with the psychological and social aspects of cancer care (Holland, 2002; Nicolas, 2013). Within the professional practice of psychology, psycho-oncology is defined as a subspecialty by the Commission for the Recognition of Specialties and Proficiencies in the Profession Psychology (2012) as cited in Nicolas (2013). In this classification, a subspecialty is a focused and narrow field of study within one or more of the recognized specialities. Psycho-oncology operating as a subspecialty generates its own set of clinical skills in counselling, behavioural and social interventions to oncology and provides training curricula which teach basic knowledge and skills in this specific area of oncology and psychology. Scientifically, psycho-oncology is creating a body of research and scholarly information about clinically relevant issues in the care of patients with cancer. Since it is increasingly recognized that psychological, social and behavioural variables influence treatment outcomes, attention to psycho-oncology will likely continue to increase (Holland 2004).

Psycho-oncology can best be described as a discipline that helps cancer patients mobilize all of their resources to live psychologically healthy with cancer. It addresses two dimensions of cancer. First, the emotional responses of patients at

all stages of the disease, as well as their families and caretakers (psycho-social) and secondly, the psychological, social and behavioural factors that may influence cancer morbidity and mortality (psycho-biological) (Haber et al., 1995; Hollard, 2002; Spiegel, 2012). Rodrigues (2008) sees psycho-oncology in the light of “where cure is unlikely, there can always be hope and spiritual support” (p28).

### **3.4.2 History and development of psycho-oncology**

A historical perspective is important for understanding current patient-medical staff- and society’s responses towards cancer since attitudes, myths and beliefs of earlier centuries remain to influences present day perceptions (Holland, 2002, 2004). Grassi (2013) emphasises the importance to recognize and understand these historical underpinnings because of their continuation to influence current thoughts and beliefs about cancer and its psychiatric comorbidity and psychosocial problems.

Traditionally the diagnosis of cancer and its prognosis were hold back from patients for centuries due to the “stigma” and fears attached to cancer. In the 1800’s, as in the preceding centuries, a cancer diagnosis was viewed as the equivalent of death for there was no cure for the disease. It was considered cruel and inhumane to reveal such a diagnosis to the patient because he/she would lose all hope and could cope better by not knowing. Since there was also no cause identified for the disease, shame and guilt were dominant emotions combined with the fear that cancer might be contagious (Holland & Weiss, 2010). This custom of keeping the diagnosis quiet prevented communicating with cancer patients about their feelings and experiences and how they were coping with the disease and the possible threat of death precluding any studies in that field. The stigma surrounding cancer was diminished only during the seventies to the point where the diagnosis could be revealed to the patient self and the thoughts and emotions of the cancer patient and his family could formally be studied. For the first time it was also possible to educate the public about cancer, cancer prevention and cancer treatment (Holland, 2004; Holland & Weiss, 2010). However, a second stigma around cancer has contributed to the delayed development of interest in the psychological dimensions of cancer, namely the prejudice about mental illness and psychological problems even in the context of a



medical illness such as cancer (Holland, 2004). Holland stated that patients still fear being labelled as 'psychiatric', or 'psychological' or 'weak' if they seek psychological help. To beat this obstacle, cancer patients should be able to consume psycho-social services in the oncology clinic and experience it as fully integrated into their total oncology care. The cancer patient must see the mental health professional as a member of the oncological team, with evaluations and clinical services given at the same medical location (if possible) where they receive their oncology treatment in order to reduce the barrier that comes from experiencing psycho-social services as separate and 'different' from their medical treatment.

The formal scientific beginnings of psycho-oncology can be dated back to the work of Arthur, M. Sutherland (1910-1971) who was a true pioneer in the field of cancer and cancer care. He was an attending physician and psychiatrist and head of research psychiatry in the Department of Medicine at the Memorial Hospital in New York from 1949 to 1961. This was the first formal psychiatric unit established in a cancer hospital (Holland, 2004). Sutherlands' work was an epitome of total commitment and dedication to improve psychological care of cancer patients (Grassi, 2013; Sutherland, 1957). Sutherland had distanced himself from the psycho-somatic etiological hypothesis of cancer, instead advocating the theory that the psychology of the cancer patient is the psychology of any person under an unusual and severe form of stress during which many basic underlying emotionally charged beliefs based on the life history of the patient and his or her experiences, are brought to the surface (Grassi, 2013; Sutherland, 1957). Sutherland (1957) implied that each cancer patient must be considered as an individual with a specific type of cancer and that each patient must be handled in the light of his/her unique context, for every person must make her own adjustment to the circumstances of his/her particular kind of cancer and its treatment. To Sutherland, adjustment to cancer was never independent of concurrent life situations, but on the contrary, both life experiences and the patterns of adaptation fundamentally influence each other. In terms of family support and the cancer patient, Sutherland (1957) considered the importance regarding the background of the relationship between the patient and his or her family taking into consideration certain variables belonging to the family system, for example, the prior marital relationship

or reciprocal support and interrelation. Sutherland also examined the role of culture and ethnicity and the different meanings and values as a significant variable to assess when dealing with cancer patients who are in need of continuous care.

Sutherland (1957) described the cancer patient as long-lasting, subjected always to the threat of recurrence, complications of altered anatomical sequelae, motional disturbances in herself and her family and to the prejudices of the ignorant. The cancer patient, in his view, needs on-going sympathetic contact even if it is at long intervals. Taking into consideration all of the above mentioned elements (psychological, family and culture) and the integration of these elements developed by Sutherland, it became the foundation for a holistic development and understanding of the cancer patient and her family. Sutherland made it very clear in his pioneer work that both science and compassion should be part of the same integrated approach to cancer and should be the core of psycho-oncology. Instrumental (cure) and affective (care) dimensions are complementary part of the oncology profession and without any one of the two, the integrity of the profession collapses (Grassi, 2013).

Around the late 1970s, the behavioural medicine movement had begun to develop and brought an important group of researchers to the psycho-social aspects of cancer, mainly in Germany, the United Kingdom, Australia, Canada and the United States. Clinical and health psychologists have contributed new and valuable dimensions to this research, presenting theoretical models of coping and cognitive-behavioural models of psychological interventions. This development of theoretical models has been critically important for building on psycho-social and behavioural interventions in cancer care (Barry, Bultz & Johansen, 2011; Holland, 2004).

It is important to recognize that the development of psycho-oncology into a subspecialty in oncology and psychology has been the result of the efforts of several pioneers in the field (Holland, 2004). What makes it remarkable is that these pioneers of psycho-oncology came from around the world and represented different generations and sub-categories in medicine and psychology. The International Psycho-Oncology Society (IPOS) has formed the Sutherland

Memorial Award in the early 1980s which has been granted to nine developers/pioneers to honour their life-time contributions to psycho-oncology. I have summarised from the work of Holland (2004) the works and contributions of these nine men and women in order to understand where and how psycho-oncology has developed. The dates in brackets are the year when they were granted the award:

- Avery Weisman (1982): A professor in psychiatry in Massachusetts General Hospital was honoured for his early psycho-social studies in the 1960's. His concepts of existential difficulty and coping mechanisms still remain revolutionary and inspirational today. In spite of his training in neurology, psychiatry and pathology, he has commented that nothing had prepared him for dealing with terminal ill patients. With his interest in the psycho-social side of death, he embarked on a multifaceted quest of understanding how people live with the prospect of death which culminated in his book 'On Dying and Denying: A Psychiatric Study of Terminality' – 1972 (Holland, 2004; Kastenbaum, 1993).
- Bernard Fox (1984): PhD, statistician at the National Cancer Institute in the United Kingdom. Fox took a personal interest in the development of psycho-social oncology, its initial research and the problems of developing valid instruments of high quality. He edited the reports of the first meeting of psycho-social oncology researchers in 1975, and he continued to review research in this field with a critically constructive eye. He was also a founding member of IPOS.
- Morton Bard (1987): PhD, social psychologist. Dr Bard was a graduate student with the Sutherland group at Memorial in the early 1950's and his main interests were in institutional and attitudinal barriers to psycho-social care. He set a high standard for research in the psycho-oncology field and he later guided the Cancer Control Division of the American Cancer society in the 1991 (Holland, 2004).
- Margit von Kerekjarto (1991): PhD, psychologist from Germany. She was one of the earliest researchers in the field of psycho-oncology. Dr Kerekjarto directed psycho-social research and clinical care in the department of psychological medicine at the University of Hamburg in the

1980s. She was also a Founding Member and president of IPOS and played an instrumental part in its early development, especially in Europe.

- Ned Cassem (1993): MD. Dr. Cassem practised as a psychiatrist and Jesuit priest, and has brought a significant contribution to the psychological and spiritual domains of palliative care. He founded the first hospital ethics committee in the United States which remains up till today a model.
- Steve Greer (1996): MD. Dr. Greer was one of the early contributors to psycho-oncology, defining and measuring 'fighting spirit', and its role in coping and survival. He developed adjuvant psychotherapy as a cognitive-behavioural evidence-based intervention.
- Kawano Hiroomi (1998): MD. Dr. Kawano was a radiotherapist from Kobe in Japan. He had a strong and compassionate commitment to psycho-social and palliative care. As a Founding Member of IPOS, he continuously supported the society's international works and was an invaluable leader. IPOS has honoured him for his early leadership in Japan by establishing the Kawano Young Investigator Award.
- Robert Zittoun (2000): MD. Dr. Zittoun an oncologist in Paris was also a founding member of IPOS. He had hosted the first world congress of psycho-oncology in Beaune, France, which was the home of the first hospice. He had a strong positive influence on the development of psycho-oncology in Europe and was involved in the first international symposium in 1999.
- Jimmy, C. Holland (2003): MD. She received the 9th Sutherland Memorial Award. She was at the first meeting on psycho-social issues in 1975 and was the founding president of the International Society in 1984 and of the American Psychosocial Oncology Society in 1986.

Grassi (2013) summarises Sutherlands' contribution to psycho-oncology by saying that Sutherland applied to oncology the patients' personal experience of the disease and how this meaning may influence his or her behaviour towards the illness and interaction with others. Therefore, human life should be viewed as wholeness, demanding and deserving both the tough-mindedness of the scientist

and the compassion of the physician, integrating the cure and the care as inseparable quantities of the medical methodology.

### **3.4.3 Challenges and obstacles in psycho-oncology**

The road of development in psycho-oncology was not without hurdles and difficulties. One of the earlier prominent obstacles in the development of psycho-oncology was the fact that there were only a few assessment- and validated instruments and research methods in terms of the psychological and social side of cancer that were available to the bio-medical community (Holland, 2004). Over the last quarter of the 20<sup>th</sup> century, outstanding progress was made in developing validated, quantitative measurements for pain, anxiety, fatigue, major depression, multidimensional quality of life and spiritual beliefs. The international body of psycho-oncology encourages researchers to use central instruments so that comparison will be possible across studies. I have selected a few of the psychometric tests to describe here. These tests were standardised and validated specifically for cancer patients and are used worldwide in the psycho-oncology setup. Vodemaier and colleagues (2009) stated that brief but validated questionnaires would seem to be the tools of choice for routine screening of cancer patients' emotional distress. They said that brief self-reports are easy to manage, inexpensive and can help identify patients most in need of professional mental health support. Examples of these tests are:

- (a) The BSI-18 is a self-report scale that was designed to assess clinically relevant psychological symptoms and demonstrated excellent reliability and validity in mixed samples of cancer patients.
- (b) The Zung Self-rating Depression Scale is a 20 item questionnaire that evaluates depression in cancer patients.
- (c) Another scale for depression and anxiety is the Hospital and Depression Scale (HADS) who was specifically developed for use with physically ill patients and is widely used to measure psychological morbidity in cancer patients (de Haes, van Knippenberg & Neijt, 1990; Vodermaier, Linden, & Siu, 2009).
- (d) The 21-item Psychosocial Screen for Cancer was developed to assess six domains: depressive symptoms, anxiety symptoms, quality of life (global),

and quality of life (number of days impaired), perceived social support, and social support desired (Vodemaier et al., 2009).

- (e) The Fatigue Symptom Inventory (FSI) was established as a valid and reliable measure of fatigue in cancer patients (Hann et al., 1998).
- (f) The Rotterdam Symptom Checklist (RSCL) was developed to monitor the quality of life of cancer patients and is also applicable for measuring the levels of the cancer patients' anxiety and depression (Trew & Maguire, 1982).
- (g) The Distress Thermometer (DT) which was validated by the National Comprehensive Cancer Network (NCCN) and the psycho-social distress practice guidelines panel and is a brief self-reporting screening tool that measures sources of distress and distress levels (Zwahlen, Hagenbuch, Carley, Recklitis & Buchi, 2008).

Another research barrier was the fact that there were only a small number of clinicians and investigators involved in psycho-oncology world-wide. Because they came from different countries, disciplines and back grounds there was not a natural and clear shared body of knowledge (Holland, 2004). Because of this gap the International Psycho-Oncology Society (IPOS) was founded. Despite these obstacles, at the start of the third millennium, psycho-oncology has come of age as one of the youngest sub-specialties of oncology and as one of the most clearly defined sub-specialties of consultation-liaison psychiatry, representing an example of the value of a broad multidisciplinary application of the behavioural and social sciences (Dolbeault, Szporn, & Holland, 1999; Holland, 2002; Holland, & Weiss, 2010; Suls & Rothman, 2004). Holland (2002) claims that over the next 25 years there will be a further improvement in the psycho-social care of patients based on research that gives a scientific basis for interventions and a reduction in the barriers to psycho-social care in cancer. Miles (2012) has asked the question if the integration of science and compassion in oncology has been reached after all these years. He asked whether there are any scientific data in psycho-oncology showing that both cure, in the sense of bio-medical intervention and care, in the sense of compassion, respect, and concern for the other, are now part of a whole approach to cancer.

#### **3.4.4 The development of the international psycho-oncology society (IPOS)**

The International Psycho-Oncology Society (IPOS) was founded in 1984 to create a network for the small but active teams of multidisciplinary clinicians and researchers throughout the world and to assist engaging in clinical, educational and research aspects of psycho-oncology. One of the aims of IPOS is to serve as an organization for cross-cultural collaboration and international meetings where research could be presented. Founding members originated from seventeen countries, generating a rich international perspective to the field of psycho-oncology (Holland, 2004). In parallel with IPOS, the British Psycho-Oncology Group (later BPOS) was first formed in 1983, while the American Psycho-Oncology Society met annually in conjunction with the Academy of Psychosomatic Medicine, and eventually the First IPOS World Congress was chaired by Robert Zittoun in France in 1992.

The standards of IPOS were conceived and endorsed at the IPOS World congress in Vienna in 2009 (Breitbart et al., 2013). These two standards are:

- Quality cancer care must integrate the psycho-social field into routine care.
- Distress should be measured as the 6<sup>th</sup> vital sign after temperature, blood pressure, pulse, respiratory rate and pain. Vital signs are measurements of the body's most basic functions and The International Psycho-Oncology Society (IPOS) endorsed distress as the 6th vital sign in June 2009. (Breitbart et al., 2013; Bultz & Johansen, 2011).

To ensure universal acceptance and implementation of the IPOS standards, it will require training, funding and supporters and advocates at the individual country level, and a firm commitment from cancer care professionals and cancer care leadership from global authorities (Bultz, Cummings, Grassi, Travado, Hoekstra-Weebers, & Watson, 2014). According to the very recent article by these authors, patients still do not always experience whole patient care due to the fact that providers not always embrace new approaches to care delivery because changing practice collides with values they hold about their current practise. The IPOS federations therefore aims to represent psycho-oncology societies worldwide and

create a plan/policy for promoting optimal psycho-social care at all stages of the disease and survivorship to all cancer patients and their families.

A second aspect that guides this commitment of IPOS standards was the importance of cross-cultural aspects in psycho-social oncology. The different styles in which cultures approach communication and doctor-patient relationships, for example, disclosure of information related to diagnosis and prognosis and the roles of patients and family in the decision-making process, represents a major area related to psycho-oncology and cultural competence in psycho-oncology. It is imperative to understand the cultural variables affecting screening and assessment of psycho-social distress for unaddressed psychological and social needs implicate not just challenges for the patients and their families, but also strain the health care system and the community at large (Bultz et al., 2014).

During the 14<sup>th</sup> world congress of IPOS in Brisbane, 2012 (Breitbart et al., 2013) it was again underlined that cancer services and care should include both mental and physical health with the driving principle standard (which was borrowed from the World Health Organization's 2001 report) that there is no health without mental health interrelated with the patients' disposition to see them as a person and not their illness. The biggest task of IPOS during that time was to motivate the psycho-oncology experts to enhance clinical care and practice by encouraging closer connections between psycho-oncologists and health practitioners, health policy makers and health authorities (Breitbart et al., 2013).

One of the major problems that were discussed at the 2013 President's Plenary International Psycho-Oncology Society Meeting (that was held in Rotterdam, in the Netherlands) was the funding of psycho-oncology education which was a major problem for many members of the federation (Bultz et al., 2014). According to them there are inadequate university systems supportive of psycho-oncology, both in terms of training offered and opportunities for high level academic research. During this meeting their proposed recommendations included:

- Psycho-social care should be integrated into cancer care.
- Cancer patients' distress and quality of life should be routinely screened for difficulties and needs.



- Communication skills training for health professionals should be incorporated into their health education.
- Multidisciplinary treatment should be patient-centred.
- Psycho-social care and services should be included in comprehensive treatment programmes. (Bultz et al., 2014).

The IPOS Human Rights Task force was established in 2008 to promote awareness and assistance within IPOS and the IPOS Federation for the relevance of psycho-social cancer care as a human rights issue. This human rights issue could be advocated for internationally, through existing human right laws similar to the human rights initiative of the organized palliative care movement (Breitbart et al., 2013).

In November 2014, at the World Congress of Psycho-Oncology in Lisbon, the IPOS Board authorized the Lisbon Declaration which states Cancer Care as a human right. In 2015, IPOS included this declaration to its international standards of quality in cancer care which includes the following:

- Psycho-social cancer care should be recognized as a universal human right.
- Quality cancer care must integrate the psychosocial field into routine care.
- Distress should be measured as the sixth vital sign.

This standard has been endorsed by 75 organizations worldwide and was classified in a revision of the World Cancer Declaration. Dr Travado, current head of psycho-oncology at Champalimaud cancer centre, Lisbon, said writing and approving a declaration is important, but it does not necessarily translate into easing the lives of actual patients with cancer, for the vast majority of them still suffer without significant help. He said that the majority of the work still lies ahead. He said although they have worked hard to influence national cancer policies to include psycho-social care and have succeeded in many countries, they need to continue to carry out this goal and take further steps to turn this standard into international global clinical practice word wide (Grassi et al., 2016).

For the 17<sup>th</sup> World Congress of Psycho-Oncology, held in 2015 in Washington, DC, IPOS has partnered with the American Psychosocial Oncology Society

(APOS). The theme of the Congress was “From National to Global: Implementing the standard of psycho-social care in oncology” which defined the awareness that psycho-social care has become a recognized subspecialty of cancer in the United States and many other Western Countries. Unfortunately, this is not the case in many countries in the rest of the world, notably Africa and South America (Travado et al 2017). Grassi and colleagues (2016) gave an overview of the areas in the world where members of IPOS can be found: Africa (Psycho-oncology Society of Nigeria (POSON), North-America, South America, Europe, East Asia, Australia, New Zealand, and the Middle East. According to Grassi and colleagues (2016) there are also countries that have societies in a developing phase, including the Irish Society of psycho-oncology, The Russian Society of psycho-oncology, the psycho-oncology Society in Kenya and the Society of psycho-oncology in South-Africa.

#### **3.4.5 Psycho-oncology in South Africa**

In spite of the evidence suggesting that bio-psycho-social care is the best way to treat cancer patients, in South-Africa the implementation of this strategy is lacking (Pillay, 2001; Venter, 2014). This aspect of the management of cancer patients, especially in the early stages of the diagnosis, is often either ignored or superficially handled (Pillay 2001). Manicom (2010) claims that in South-Africa there are only a few mental health professionals with a specific interest in cancer care with a few working exclusively in an oncology setting. Research in Africa has mainly focused on opioid availability and on the bio-medical aspects of cancer, presenting a preference for the assessment of physical symptoms but neglecting psycho-social aspects and holistic care of the cancer patient (Selman et al., 2011). Venter (2014) described in her work that a bibliometric analysis of research publications during 1994-2003 done by CANSA, found that the majority of the studies focussed on the bio-medical aspects of cancer with only 16% of studies during this timeframe was focused on psycho-social factors. This author feels that despite the need for a bio-psycho-social approach, there seems to be limited literature available on the psychological adjustment of cancer patients in South Africa.

For many years South Africa has not had an active National Cancer Registry, but according to Grassi and Watson (2012), this will change in the near future. Despite difficulties such as lack of access to essential drugs, poor social conditions and lack of trained palliative care professionals, it is internationally recognised that South-Africa has made sustained gains in the provision of palliative care largely through community-based hospices and home-based palliative care services (Selman et al., 2011). According to Grassi and Watson (2012) the health department in South Africa is working on a national cancer control plan where various stake-holders have been contacted regarding such a plan in which aspects of palliative care will be included, but it is not apparent when it will be implemented. In a developing country such as South Africa, competing healthcare priorities, poor resources, cultural diversity, language barriers and the differential standards of treatment in the public and private healthcare sectors, challenge a psycho-social approach to cancer (Bateman, 2011; Pfaff, & Couper, 2009; Pillay, 2002; Venter, 2014). Patient diversity in combination with staff shortages and a lack of necessary resources to deal with the demands of the oncology environment, results in a cancer care delivery system that does not reflect the new realities of cancer survival (Maree & Wright, 2008).

Traditionally, cancer related psycho-social problems are addressed by psychologists, psychiatrists and/or social workers, but these services are not always available outside large hospitals and urban areas. This might lead to the possibility of involving other more available professionals such as nurses (Venter, 2014), and can result in uncertainty about roles and responsibilities and challenging well established territory between professionals (Arving & Holmström, 2011).

In summary: IPOS has recently advocated an international standard of quality cancer care, which declares that all cancer patients should have access to psycho-social care and that distress should be assessed as the sixth vital sign. It is a worthy goal for all psycho-social oncology societies to try to achieve, but in many countries, especially developing nations, psycho-social oncology is either not established or not completely established, or not an integral part of cancer care where basic

Bultz, 2004; Grassi & Watson, 2012). The International Psycho-Oncology Society strives to achieve a global perspective, acknowledging that psychosocial issues and the potential for implementation vary broadly by culture, economics and health care systems (Holland, 2004).

### **3.4.6 The development of clinical practise guidelines**

The field of psycho-oncology, over recent years, has seen the development of clinical practise guidelines for psycho-social cancer care in several countries (Bultz & Johansen, 2011). Clinical practise guidelines are progressively being developed in medical settings to provide evidence-based recommendations to guide the clinical care of patients. The development of clinical practice guidelines for psycho-social care of patients with medical illness is more complex and challenging as the target audience includes health care professionals from diverse backgrounds. According to Turner and colleagues (2005) clinical practice guidelines are in principle a summary of the best available scientific evidence that are presented in a format which is effective and practical to guide clinical decision-making.

The comprehensive cancer network who established a multidisciplinary panel to examine the problem of how to integrate psycho-social care into routine cancer care developed the first set of standards and clinical practice guidelines for psycho-social care in cancer in 1997 (Barry & Bultz, 2007). The panel included representatives from all the major disciplines involved in clinical care namely oncology, nursing, psychiatry psychology, chaplaincy, social work and patient advocacy (Barry & Bultz, 2007). In Australia, the National Breast Cancer Centre and National Cancer Control Initiative have cooperated to develop clinical practice guidelines for psycho-social care of adults with cancer (Breibart et al., 2013; Turner, Zapart, Pedersen, Rankin, Luxford, & Fletcher, 2005; Zorbas et al., 2003). The National Health and Medical Research Council (NHMRC) which is the uppermost scientific advisory and research committee in Australia, recommends that clinical practice guidelines should be outcome focused, integrate the best available evidence and must be developed by a multidisciplinary group which also includes the consumers (Turner et al., 2005; Zorbas et al., 2003). Currently the National Health and Medical Research Council (NHMRC) recommend that breast

cancer patients should have access to the full range of multidisciplinary treatment options (Zorbas et al., 2003). The principles of multidisciplinary care for cancer include the importance of the team approach, good communication, having access to the full range of therapies, maintaining standards of care and involving the patient in decision-making (Zorbas et al., 2003). They not only developed these practical guidelines, but also attempted to implement them by creating demonstration projects, health service delivery and clinician training, educating doctors in communication skills, monitoring programs and involving the public, mainly by forming partnerships with breast cancer advocacy groups (Redman, Turner & Davis, 2003; Turner et al., 2005).

Broad international confirmation of distress as the '6th vital sign' is considered a major step towards improving access to psychosocial care and lowering the isolation and stigma experienced by many affected by cancer (Turner, 2015). The UK has the National Institute of Health and Clinical Excellence (NICE) guidelines for improving supportive and palliative care for cancer patients, which include recommendations for implementing psychosocial care. The European Union has focused attention on cancer care with psycho-social investigators now involved in their discussions (Holland & Watson, 2011). The United States' Institute of Medicine issued a report in 2007, outlining the strong evidence for psychosocial intervention in cancer care and suggesting the inclusion of psychosocial care in clinical treatment (Breitbart et al., 2013).

#### **3.4.7 The concept of holism and the role of a multi-disciplinary team in psycho-oncology**

In psycho-oncology, the concept of holism has been the driving force for recent recognition of the importance of comprehensive cancer care as specified in the Institute of Medicine's (IOM, 2008) influential report. This report was called: cancer care for the whole patient: meeting psychosocial health needs. This report has recommended the following standard of care: All cancer care should guarantee the delivery of appropriate psycho-social health services by:

- Facilitating effective communication between patients and care providers.
- Identifying each cancer patient's psychosocial health needs.

- Proposing and implementing a plan that links the patient with needed psycho-social services and coordinates bio-medical and psycho-social care.
- Systematically following up on, re-evaluating and adjusting plans (Nicolas, 2013).

Jalil and co-workers (2012) defined the cancer multidisciplinary team as a group of individuals from different healthcare disciplines, who meet together at a given time to discuss a particular patient and who are each able to contribute independently to the diagnostic and treatment decisions about the patient. As a multidisciplinary field, psycho-oncologists come from multiple primary disciplines such as psychology, psychiatry, social work, oncology nursing and pastoral care (Jalil et al., 2012; Nicolas, 2013). Multidisciplinary teams are becoming the model of care for cancer patients worldwide, for the successful integration of psychosocial care into routine clinical practice requires active multidisciplinary engagement (Jalil et al., 2012; Turner, 2015).

The contributions from psychiatry, behavioural medicine, health psychology, pastoral counselling, social work and nursing, as well as oncologists, ethicists and patients themselves have, over the years, created a rich and diverse body of information, theoretical models and approaches, both in research and clinical interventions. The most successful psycho-oncology programs use this diversity to their advantage by evaluating cancer patients and referring them to the most appropriate therapeutic resource available drawing on the knowledge of each to enrich the others, while remaining fully integrated in the patients' total medical care (Jimmy, 2004).

According to Vetere (2007) it has long been recognized that multi-disciplinary team working in the context of physical and mental health services poses a challenge to practitioners, for often they are loyal to their own ideologies and occasionally less than accepting of others. Because of this, not referring to other disciplines, especially psychology and psychiatry, cancer patients, already known to have high rates of psychological morbidity, are low consumers of psychiatric care, especially for clinically severe disorders.

### **3.4.8 Patient - doctor communication and referrals**

Communication within oncology is a fundamental clinical skill but also one which few oncologists have received much formal training in. Sutherland has motivated already in the 1950s for specific education in communication skills for doctors working in the oncology field. Addressing cancer patients' overall needs and sharing complex and often devastating information in an already emotionally charged context and under time constraints, is a daily challenge for the oncology clinician (Bredart, Bouleuc, & Dolbeault, 2005; Sutherland, 1958). The increasing amount of information and the complexity of the knowledge about breast cancer and the number of therapeutic options now available have made discussions between cancer patients and doctors much more challenging. This is even more evident when we take into consideration that patients, already experiencing emotional confusion, now enters a new and strange world of unknown technical language and concepts (Fallowfield & Jenkins, 2013). In order to help patients to navigate their way through all this new and intimidating information about their diagnosis and to ensure that they can sincerely provide an educated and informed consent to treatment plans demands excellent communication skills from the healthcare professionals involved with cancer patients.

Inadequate communication causes distress for cancer patients and their families and they often feel that they would have liked to have more information to be provided. It consequently affects adjustment to the cancer diagnosis and patient decision-making about treatment (Fallowfield & Jenkins, 2015). Because of this, many patients leave consultations still uncertain about the diagnosis and prognosis. They are often confused about the meaning of and need for further diagnostic tests, uncertain about the therapeutic goals and treatment (Fallowfield & Jenkins, 1999). Because cancer sufferers have such a high prevalence of psychological stress and need of emotional support, it is important, from the start, that there is adequate communication about the diagnosis, prognosis and treatment alternatives ((Moore, Rivera, Grez & Lawrie, 2013).

Gandubert and co-workers (2009) claimed the failure to detect psychological distress is largely due to lack of communication between healthcare professionals and patients. Grassi (2013) referred to this as a specific field regarding the doctor-

patient communication and the importance of healthcare professional's use of empathy in facilitating cancer patient's adjustment to the illness. Moore and colleagues (2013) suggest that effective communication and support from their attending doctor or other healthcare professionals can reduce the psychological stress caused by the cancer diagnosis. This can be achieved by using effective communication and support. This is the area where both cure and care integrate with each other. There is no doubt that good communication between healthcare professionals and cancer patients' correlates well with better quality of health care influencing the rate of patient recovery and adherence with treatment procedures and overall psychological functioning (Moore et al., 2013).

According to Gandubert and colleagues (2009) doctors often think that anxiety and depression are normal reactions to the diagnosis and treatment of cancer and that such suffering will diminish over time. They therefore assume it is not necessary to pay attention to possible mood disorders or then refer the patient for further psychological help. Another barrier to adequate psycho-social care is doctors' reluctance to ask patients if they are distressed, not wanting to get into an emotional interaction because medical doctors often feel inadequate to deal with their patients' emotional turmoil (Gandubert et al., 2009). Nekolaichuk and colleagues (2011) found that in spite of the availability of psycho-social services, less than 10% of cancer patients are referred by the medical doctor for psychological evaluation and counselling and that the most common referral sources were the patients self. Kalaitzi and colleagues (2007) have found in a study that the active participation of the surgeon through referring the patient pre- or post-operative and explaining the importance of seeing a psychologist is helpful in reducing the stigma of psychological help.

As a psycho-oncologist, when working with the medical staff in the oncology setup, it is important to educate them upfront about the availability of the psycho-social services and the appropriate referral methods. Poorly managed referrals can result in hostile or reluctant patients (Deshields, & Nanna, 2010). Miles (2012) believed that today's clinicians are cautious to introduce empathetic and compassionate approaches into their care even with adequate time and opportunity and that they prefer to distance themselves from an ethical intimacy



with the patient in favour of an entirely science-based algorithmic treatment of the presenting symptoms. It is important for oncology physicians to understand the importance of not only acknowledging their patient's emotional experience, but also discuss it with them, increasing their own awareness of psychological symptoms which might enable them to seek psychological help earlier (Mello et al., 2013).

Despite the evidence of a high occurrence of psychological and social distress, emotional care for the cancer patient continues to be poorly supported by third party payers. Efficient cooperation between the various members of the health care team is also recognized to be compromised by poor communication. To improve the quality of cancer care delivery, communication in cancer care must be seen as the heart of that agenda (Thorne, Bultz & Baile, 2005). Thorne and colleagues (2005) summarized the above by stating that there are significant data to indicate that effective communication is an asset to an effective cancer system and that it is universally recognized that communication exists as a ubiquitous object in cancer care delivery.

### **3.4.9 The role of the clinical psychologist in psycho-oncology**

The development of clinical psychology started in the 21<sup>st</sup> century with an involvement in most medical specialties and across the range of setting in which health care is provided from community to hospital settings. This is contrast to the previous years where most psychologists were involved only in activities related to patients with mental illnesses, working just within mental health institutions. The variety of psychological activities incorporated currently into physical health care has also exploded in recent years. Pain is a classical area where initial simplistic models (e.g. the medical model) have been illuminated by much more sophisticated bio-psycho-social models (Britton, 2002). Specific specialties, such as obstetrics and gynaecology, diabetes and oncology now routinely make use of psychological input to patient care. It is apparent; according to Huey and Britton (2002) that there is a substantial role for the clinical psychologist in health care and that this role will continue to expand with the continuation of the development and understanding of human behaviour.

Clinical psychology, according to the British Psychological Society of 2001, can be defined as the application of psychology to health and community care. This application includes the assessment, improvement and prevention of psychological distress, disability and dysfunctional behaviour (Huey & Britton, 2002). Clinical psychology is a complex field that resembles the complexity of human behaviour and emotion. The field of clinical psychology is an integrative attempt to understand the interaction of the biological, psychological and social factors that make a person “tick”. Clinical psychology focuses on how the human psyche interacts with physical, emotional and social aspect of health and dysfunction (Plante, 2011).

The role of the clinical psychologist is to generate and integrate scientific and professional knowledge, opinion and skills to further psychological science, the professional practice of psychology and human wellbeing. A clinical psychologist can be described as a professional person with a flexible and broad knowledge of psychology which facilitates the ability to draw from a range of theories in order to devise individually tailored strategies for complex presenting problems. On a more practical side, clinical psychologists assesses diagnoses and treats individuals suffering from psychological distress and mental illness and performs psychotherapy and develops treatment plans (Huey & Britton, 2002; Plante, 2011).

Most professional psychologists who work as psycho-oncologists are likely to have been initially trained as either clinical or counselling psychologists and who have most likely received additional training at either a pre-doctoral internship or doing a Ph.D. specializing in psycho-oncology (Nicolas, 2013). It seems that in most universities (presumably also in South-Africa), cancer care as a sub-speciality in psychology is not as yet mandatory and further studies after a psychology degree is required to understand and work with cancer patients in the field of psycho-oncology.

For a psychologist to work collaboratively with cancer professionals and cancer patients, a basic understanding of cancer and its background is necessary (Haber et al., 1995; Nicolas, 2013). Understanding the specific cancer procedures, the site or bodily location of the cancer, basic information about the cancer staging and grading and their relationship to severity and prognosis, as well as an

understanding of the types of cancer treatments, such as different types of surgery, radiation and chemo- and hormonal therapies will help the psychologist to assist the cancer patient better on psychological grounds (Nicolas, 2013). It is also important to be knowledgeable about the degree of pain of the cancer patient; the side-effects of the various cancer treatments, probable level of functioning and the quality of life the patient might be able to expect (Haber et al., 1995; Nicolas, 2013). Haber and colleagues (1995) stated that by having a working knowledge of the medical issues the breast cancer patient will encounter, the psycho-oncologist can assist and support the patient (and her family) emotionally, facilitate decision making during the trajectory of treatment and function as a liaison between the patient and her physician. Understanding the medical issues makes it easier for the psychologist to “normalise” fears, anxieties and myths in order to stay focused on the psychological reactions without becoming distracted or overwhelmed by the medical component. According to Haber and colleagues (1995) the three major relationships to consider from the side of the psychologist are: the patient-physician relationship, the psychologist-physician relationship and patient-psychologist relationship, with the most significant, the patient-physician relationship. There need to be open channels of communication between the psychologist and the physician through which necessary information can be shared. According to these authors, there must be at least one meaningful interchange of information during which they can share relevant information and can discuss their particular assessments and treatment plans.

#### **3.4.10 The bio-psycho-social model in practice**

In my attempt to understand the world of the breast cancer patient, I have done a thorough professional literature study of both the physiological side of cancer in the framework of the original bio-medical model of Louis Pasteur and the modern psychological side based on the psycho-social model from Engel. This knowledge that I have acquired from the literature is non-empirical for it is independent of any experience. The empirical data will be obtained and tested through a qualitative approach where I have studied breast cancer patients in their particular and unique social milieu in various stages and time frames in the trajectory of their cancer. The aim of my researching attempts was to lessen the distance between myself and my research objects cooperating and spending time in the field with

them and become an “insider” in their worlds (Creswell, 2007). This fits in with the constructionist approach, which was the most suitable epistemological paradigm for my qualitative research and agreed with my notion that studying people’s lived experiences occur within a particular historical and social context (Ormston, Spencer, Barnard, & Snape, 2014; Soini et al., 2011). This fits in with Omar and colleagues (2014) proposal that social research should explore lived experiences in order to reveal the connections between the social, cultural and historical aspects of people’s lives and to see the context in which particular actions take place. Constructivism is the understanding of reality as a social construction and not as an objective truth and that there exist multiple realities associated with different groups and perspectives (Soini et al., 2011).

The application of the bio-psycho-social model in my therapeutic interventions relies on all the core principles of this model with the most important one that of integrating body and mind. Combining the knowledge of the biology of the cancer and the cancer treatment with the social and psychological impact on the patient and her family I have attempted to work within the holistic framework proposed by this model. Even in private practise I strive to work within a multi-disciplinary team with special effort to effectively communicate with the oncologists, making sure that they are informed of my professional services and location and also to be aware of other relevant professionals in case I have to refer a patient to another speciality. The knowledge generating from the bio-psycho-social model assist me in assessing and treating the cancer patient psychotherapeutically in order to enhance her quality of life and prevent the development of serious psychiatric disorders like depression or anxiety.

In accepting the “human side” of the cancer patient, it allows her the freedom and professional environment to express her experiences without feeling judged or ashamed of how she feels and it validates her as a person. Psycho-therapy can teach her to take control in a situation with very little control, empowering her to take part in the decision- and treatment process with her oncology team and can teach her (new) effective skills to cope with this new and challenging journey. Because of the whole holistic point of view, the cancer patient is treated not in isolation, for her illness is part of her marriage and family and by involving them it

improves and develops the whole family and social structure enriching the support system.

## **CHAPTER IV**

# **PSYCHO-ONCOLOGIC INTERVENTIONS FOR THE BREAST CANCER PATIENT**

### **4.1 INTRODUCTION**

The word cancer, due to its continuing ominous threatening symbolic implications, still has toxic connotations in all cultures that discourage patients and their families from seeing cancer as a disease with varied outcomes, including cure. Demystifying the word cancer will require the combined and determined efforts of the oncology team, patients, families and media to generate a new culture of care in oncology (Surbone et al., 2013).

McQuellon and Danhauer (2006) use the term “psycho-social rehabilitation in cancer” and define it as the process by which physical, mental and social abilities are reconditioned or developed for people with disabling conditions. In 1989, the Oncology Nursing Society has defined cancer rehabilitation as a process by which individuals are assisted, within their circumstances, to achieve optimum functioning within the limits imposed by their cancer (McQuellon & Danhauer, 2006). According to these authors, the growing body of literature supporting the effectiveness of psychological- and social interventions in the rehabilitation of cancer patients are driven by the increasing number of cancer survivors and the fact that there are fewer stigmas attached to employing psycho-social services such as counselling.

Presently, psychological treatment is increasingly acknowledged as an essential part of the comprehensive care of the cancer patient. Apart from the importance of implementing psychological care, improving the cancer patients’ access to psychological care and the availability of this care are just as important and remains a critical issue (Jacobson & Jim, 2008). The barriers that keep many patients from benefitting from psychological care services include under-recognition of the need for psycho-social care by the primary oncology team and even when recognized, the lack of professions available in many communities to

provide psycho-social care to cancer patients (Jacobson & Jim, 2008). Psycho-social care that is ineffective may be worse than no care at all. With the many different types of psychological- and social care available, combined with a growing body of research that can serve to guide practice, clinicians have a responsibility to provide their patients with the care that is likely to be beneficial for their specific type of problem they are undergoing (Jacobson & Jim, 2008). The use of research to guide practice is at the centre of evidence-based medicine. This is a movement that seeks to integrate individual patient care with the best available research evidence. As the practice of oncology attempts to be evidence-based, so too should the psychological- and social care of the cancer patient be evidence based (Jacobson & Jim, 2008; Mens, Helgeson, Lembersky, Baum, & Scheier, 2016; Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). I have found in my own practise that in spite of being a qualified clinical psychologist with twenty six years' experience in the field, there is a huge gap in specialised knowledge about cancer and cancer related psychiatric conditions and the implementation of interventions in this population. Globally, psycho-oncology is not a subject that is necessarily comprised in the academic syllabus in psychology and must be seen as an extra speciality by doing either a Master's degree or a Doctorate in this sub-speciality in the field of psychology. It is not a given that by practicing as a psychologist or clinical psychologist, you have the necessary knowledge to treat cancer patients. It is also important for the oncology team to be able to distinguish between the different specialities in terms of psychological and social care, for example, a clinical psychologist, a counseling psychologist and a social worker and what their different roles comprises.

## **4.2 AIMS AND BENEFITS OF CANCER-RELATED THERAPEUTIC INTERVENTIONS**

Women with breast cancer endure many demanding and anxiety-rousing treatments and side-effects of these treatments, along with the unpredictability of the disease, uncertainty about the future, unmet expectations about recovery, vulnerability to recurrence of disease and changes in relationships and self-image (Lee, 2008; Visser, Garssen, & Vingerhoets, 2009). Although it remains true that the central challenge of cancer is to eliminate the disease (bio-medical model), it is widely recognized now that the disease per se is not the only source of worry, nor

is it the only target for intervention. The subjective quality of the patient's life is important too, whether the amount of life that remains to the patient is long or shorter (bio-psycho-social model) (Lechner et al., 2009).

In a study done by Nekolaichuk and colleagues (2012) they have found that the distress and need for psychological interventions of their study participants could be divided into four subthemes:

- (a) Difficult and overwhelming impact and emotions they had experienced in relation to cancer.
- (b) Concerns about the impact of their cancer on their families.
- (c) Their capacity to cope with the intensity of what they were experiencing.
- (d) The reappearing of emotional difficulties after treatment completion.

The primary aim in cancer intervening therapies is to enhance the quality of life of the breast cancer patient and survivor (Blake-Mortimer, 1995; Hopko et al., 2011; Salonen, 2011). Results found in a study by Rehse & Pukrop (2003) clearly confirmed the overall hypothesis that psycho-social interventions reveal a positive impact on quality of life in adult cancer patients. It can no longer be taken for granted that successfully treated cancer patients just take up their lives where they had left off before the cancer (Carver, 2005). The concept of quality of life was first seen in the form of issues of functionality e.g. whether a patient was free enough from pain and fatigue to be able to engage in normal daily activities, if not, it was seen as an impairment of quality of life. Recently, the concept of quality of life is understood to be broader than these functional issues and is considered a multidimensional concept which comprises biological, psychological, social and spiritual life domains (Carver, 2005; Golden-Kreutz et al., 2005; Spiegel & Rodrigues, 2008).

Health-related quality of life is considered an important endpoint in clinical cancer trials. It has been shown that assessing quality of life in cancer patients could contribute to improved treatment and could even be as prognostic as medical factors could be prognostic. Among the studies done on quality of life in cancer patients, breast cancer has received most attention for several reasons, including that the number of women with breast cancer is increasing and because of early



detection and improved treatment breast cancer survivors now live longer, therefore the studying of quality of life in this context is important (Mehnert & Koch, 2008; Montazeri, 2008). Montazeri (2008) believed that women play important roles as partners, wives and mothers within any family structure, thus when she develops breast cancer all members of the family might develop some sort of disorder. This author actually feels so strong about this fact, that he considers breast cancer as a family disease which has the power to disable the quality of the lives of the whole family.

Another aim of psychological intervention is the proactive management of distress levels of a breast cancer patient in order to prevent the development of more serious psychiatric problems like depression, anxiety or post-traumatic stress disorder. It is already established that breast cancer patients often develop psychopathological disturbances during their medical treatment or during their remission phase (Berger et al., Brem & Kumar, 2011; Dolbeault et al., 2009; Hill, et al., 2010; Nekolaichuk et al., 2011; Reyes-Gibby et al., 2012). The importance of early diagnosis and intervention of depression, anxiety and post-traumatic stress disorder can never be over emphasized for it is not only beneficial to enhance short term quality of life, but would likely decrease the negative impact of stress on long-term quality of life which can lead to impaired social and occupational functioning (Cielito et al., 2012; Dolbeault et al., 2009; Golden-Kreutz et al., 2005; Meier, 2010; van Oers, 2013). One of the goals to improve the quality of life during breast cancer is by reducing emotional distress through better coping mechanisms and skills with daily difficulties, especially during the treatment phase. Identifying and understanding one's stressors and learning to cope with it successfully through learning and applying new skills can cause higher levels of spirituality and appreciation for life, all contributing to higher quality of life (Park et al., 2008).

According to Livneh (2001) good quality of life is often seen as the fundamental and ultimate goal for people with a chronic condition and that successful acceptance and adaptation will be reflected in the person's capability to re-establish and manage the external environment and inner cognitions, feelings and behaviours. A longer term goal would be to empower breast cancer patients with general life skills and mechanisms beyond their current stint with cancer (Carver,

2005). The most frequent and well-studied psychological- and social interventions or treatments to enhance quality of life for cancer patients cover a wide range of approaches, many comprising multiple components such as education regarding cancer and its treatment (psycho-education), emotional support and expression (supportive therapy), cognitive- and behavioural therapy, relaxation training, problem-solving training and stress management (Fawzy & Fawzy, 2001; Hopko, Robertson & Colman, 2008; Livneh, 2001; McQuellon & Danhauer, 2006; Spiegel & Rodrigues, 2008). The aim through all of these interventions is to enable the breast cancer patient to take control of, and participate in their lives again as it will increase their self-efficacy and quality of life and reinstate their self-esteem, identity and confidence (Brennan, 2001). Psychological interventions should enable the breast cancer patient to face their future with hope alleviated by awareness and realistic expectations and arm them with the knowledge that lifetime follow-ups and care of potential long-term treatment sequelae will be necessary to achieve and maintain good quality of life (Hopko et al., 2011; Surbone, Annunziata, Santoro, Tirelli & Tralongo, 2013).

#### **4.3 INDIVIDUAL PSYCHOTHERAPY AND CANCER-RELATED INTERVENTIONS**

Individual psychotherapy can be defined as a formal process of interaction between a trained therapist and a patient working in a confidential, safe and caring environment for the purpose of improving distress through exploring the patients' beliefs, behaviours, feelings and thoughts (Wedding, 2010).

Individual treatment sessions, which allow the intervention to be tailored to the patients' unique physical needs, might be more effective than group therapy for all breast cancer patients, but especially in metastatic and terminal breast cancer patients with psychological disorders (Beltman et al., 2010; Savard et al., 2005). This was confirmed by a Meta analyses done by Osborne and colleagues (2006) who indicated that cognitive-behavioural therapy is effective for both short- and long-term management of quality of life for cancer patients and had better results in individual, goal oriented sessions than that of group interventions. Although group therapy and the benefits of group therapy for cancer patients have received considerable attention in literature, it may not always meet the needs of all cancer

patients (Blake-Mortimer et al., 1999; Breitbart et al., 2010; Classen et al., 2001; Nekolaichuk et al., 2012). Individual psychotherapy is mostly chosen by patients who prefer one-on-one attention and support, or patients with advanced disease who need individual sessions that can be flexibly tailored to their own individual needs, taking into account their other clinic or hospital appointments as well as fluctuations in health status (Lo et al., 2014; Nekolaichuk et al., 2012). Unlike traditional therapy, working in a cancer setting can require consultations taking place in challenging environments, e.g. due to time, distance or energy constraints, the cancer patient may request from the psychologist to be seen while receiving chemotherapy or while hospitalised where they are in an area that other patients are in close proximity, limiting or making privacy practically impossible (Deshields & Nanna, 2010).

It is important for the psychologist working with cancer patients to understand that there is often limited contact with a patient due to the illness, time, distance or medical insurance and by necessity assessment and treatment must often be done during a single visit. Experts in brief psychotherapy (Deshields and Nanna, 2010) consider the first appointment also to be an intervention session. In the concept of individual psychotherapy, working with cancer patients, the challenge that distinguishes this work from most other psychotherapies is the flexible identification of “who” the patient is, for cancer patients often bring a family member or members with them into their sessions (Deshields & Nanna, 2010). The reason for this is that the cancer patient often wants her husband or child (or children) or even sometimes parents, to understand the psychological part of their cancer and to facilitate communication between them about the cancer experience and sensitive topics like death and dying. Although there are studies done on the benefits of individual psychotherapy with cancer patients, as mentioned above, Nekolaichuk and colleagues (2012) feel that the research focusing on the benefits of individual psychological counselling for cancer patients is still limited, emphasising the need for further formal evaluations in this area. I will attempt with this study to demonstrate that individual psychotherapy can have an important place in psycho-oncology for it provides a flexible environment for the exceptional needs of the breast cancer patient.

## **4.4 THERAPEUTIC INTERVENTIONS FOR BREAST CANCER PATIENTS**

In the ever changing world of cancer care, exploring psychological treatment approaches that are holistic and which accentuate the role of the patient in the healing process is essential. It is a reasonable hypothesis that if a cancer patient feels psychologically better it will contribute to her physical recovery and an overall better quality of life (Spiegel & Rodrigues, 2008).

### **4.4.1 Patient-active model**

The patient-active approach falls into the category of the bio-psycho-social model (Borrel-Carrio et al., 2004; Steward, 2001) and is best described as a goal directed and gradual approach that is determined by the patient's illness profile and treatment schedule as well as their performance status, social circumstances and personal resources prior to treatment (Greeff, 2008).

This patient-active approach builds open communication and mutual respect in the doctor-patient relationship (the medical relationship) with clear patient-centred focus no matter what the treatment outcome. This method counteracts the conventional hierarchical medical model, with power entrusted only in the medical team, but places the patients at the centre of the care model in a way that will facilitate their own healing in a patient-focused holistic care model (Greeff, 2008). Patients and their families following a patient-active approach move much earlier from victim to survivor. According to Benjamin (1995) combining the will of the patient with the skill of the oncology team, will create a powerful combination in the fight against the enemy (cancer). People with cancer who participate in this "fight" for recovery will improve the quality of their lives, especially by preventing the development of serious psychiatric problems such as depression and anxiety which then will contribute and promote their physical recovery (Benjamin, 1995; Greeff, 2008; Husson, Mols & van de Poll-Franse, 2011).

The aims and benefits of the patient-active model are as described by Greeff, 2008):

- To motivate the breast cancer patient largely through psycho-education to become involved in making active choices in her treatment process.

Patients who are given relevant information through psycho-education are able to ask relevant questions concerning their illness and treatment, which will place bigger pressure on the medical team as they have to accommodate these questions and provide information that can assist the patient in her treatment decisions. Patients with access to the internet will often question technical issues relating to treatment such as targeted therapies, how it works, the side-effects and the development of new drugs and treatment options. This creates space for the more analytical patients to ask questions to the oncology team that will ensure greater involvement and compliance and a better tolerance of treatment with most probably a more effective post-treatment adjustment.

- This approach necessitates the development and use of a multidisciplinary oncology team and for the members of this team to make use of all their resources and ensures that the patients are referred to other professions such as physiotherapists, nutritionists, biokineticists, psychologists or other complementary therapists depending on their needs, guaranteeing the development of an individualised rehabilitation plan.
- Through this model the psychologist encourages and inspires the patient to participate in a therapeutic process and to take control of the illness by developing a better understanding of their cancer and its treatment through knowledge and by learning mentally to live beyond the cancer experience.
- The emotional load carried by the medical team in terms of the patient's response (especially emotional response) to treatment becomes a shared responsibility between the specialist and the patient. Communication might be challenging and may require more preparation and input (especially) during the initial stages and at the end of treatment, but the shared responsibility of this patient-active model will create a new dynamic between the patient and the medical team leaving both the multidisciplinary team members and patients feeling less overwhelmed by the burden and responsibility they are holding (Benjamin, 1995; Greeff, 2008).
- The patient-active approach to cancer care will encourage patient independence and self-sufficiency throughout the cancer journey by taking

control of their lives through developing and working toward realistic, achievable and new goals and hope.

- This model proposes educating and encouraging the patient to learn and develop new skills in terms of their thought processes and emotions, to handle their cancer better and to improve their own quality of life through active therapeutic interactions.

#### **4.4.2 Specific therapeutic techniques in practise**

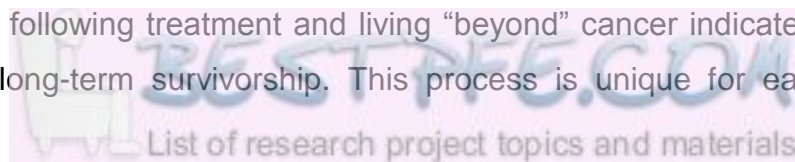
The specific therapeutic techniques that I predominantly use in my practise working with cancer patients are techniques that are well studied and described in literature regarding their applicability to the context of cancer. This include an emotionally supportive framework to address fears and anxieties about the cancer, psycho-education to give information to the patient about the disease and treatment, behavioural coping strategies for changing overt behaviour, cognitive therapy for restructuring irrational thoughts and learning coping strategies, and psychological acceptance and adaptation of the illness (Anderson, 1992; Fawzy, Cousins, Fawzy, Kemeny, Elashoff, & Morton, 1990; Forst et al., 2010; Golden Kreutz et al., 2005; Hopko et al., 2008; Hulbert-Williams, Neal, Morrison, Hood, & Wilkinson, 2011; McQuellon & Danhauer, 2006). Studies assessing the usefulness and effectiveness of these interventions, provide substantial verification that they effectively reduce symptoms of depression, anxiety and pain and improve overall quality of life in the breast cancer population (Baum, & Andersen, 2001; Hopko et al., 2008; Hulbert-Williams et al., 2011). Using these psychological interventions to decrease psychological distress and improve quality of life should be applied flexibly to meet the specific type of adjustment difficulties presented by the cancer patients throughout the trajectory of their treatment and thereafter (Hulbert-Williams et al., 2011). A good example of this flexibility is to understand and address psychological interventions with cancer patients in a specific time line predicted by the illness self and the treatment. Anderson (1992) and Mullan (1985) have identified three stages of the disease time line:

- (a) The acute stage: This stage begins with the diagnosis of the cancer where the focus is on the trauma of learning one has a potentially life-threatening illness, through the active treatment stage. Mullan (1995) describes anxiety,

fear and pain resulting from both the illness and treatment as constant elements of this phase. This stage is defined by both the experience of the person diagnosed with cancer and by those of the family members who are affected by the diagnosis.

- (b) The extended stage: This stage can be described as immediately post-treatment and begins when the survivor goes into remission or has completed the treatment (or it can be through extended treatment (Anderson, 1992). Anderson, who is himself a cancer survivor, said that psychologically, this stage is a time of waiting and wondering if any given symptoms that you may experience, may be signs of recurrence or just a part of everyday life. The ending of the treatment can also cause acute anxiety because of the sudden diminished contact with the health care team. During this stage, the survivor becomes aware of and learns to live with the chronic side effects of the illness and its treatment, even if the treatment is finished.
- (c) The permanent stage: This stage can be defined as a time when the likelihood of the return of the cancer is sufficiently small and that the cancer can be considered “permanently arrested” (Mullan, 1995, p272). Mullan acknowledged however, that this stage is more complex than simply the status of the disease (in this case, in remission). A cancer survivor in this stage may face financial and social challenges, fear of recurrence and secondary effects from the cancer treatment (e.g. fatigue, decreased memory, etc.). End-of-life concerns can occur during any of the three stages. End-of-life care confirms life and regards dying as a normal process with the goal of end-of-life care to achieve the best possible quality of life for the cancer patient by controlling pain and other symptoms and addressing psychological and spiritual needs.

To summarise the three stages, Mullan (1995) defines the experience of cancer survivorship as living “with” cancer, living “through” cancer and living “beyond” cancer. Living “with” cancer implies the experience of receiving the cancer diagnosis and the treatment that may follow. Living “through” cancer refers to the extended stage following treatment and living “beyond” cancer indicates the post treatment and long-term survivorship. This process is unique for each cancer



patient and the passage from one stage to the next may not always be clearly outlined.

#### **4.4.2.1 Psycho-education**

Psycho-educational as an intervention technique is a therapeutic process where information and education are proposed to individuals with psychological- and physical disorders. These interventions can fluctuate from the delivery of passive materials such as leaflets or any reading material regarding the subject, or information websites, or it can be active multi-session interventions with therapist-guidance (Donker, 2009). Psycho-education is one of the most frequently used interventions in treating breast cancer patients through educating them in cancer and cancer treatment used in combination with cognitive-behavioural therapy (Donker, 2009; Fors et al., 2010; Spiegel & Rodrigues, 2008).

Psycho-education, as part of psychotherapy, can be defined as a therapeutic focus in which patients learn practical and positive emotional and behavioural skills through information and knowledge to improve life adjustments and management of self-awareness and emotions. A psycho-educational approach values the importance of education in changing unhealthy and negative emotional and behavioural patterns through information/knowledge and proactive guidance (Authier, 1977; Berger et al., 2015; Fors et al., 2010). Psycho-education teaches patients personal and interpersonal skills and attitudes which he/she can apply to solve present and future psychological problems and enhance quality of life (Authier, 1977). The providing of education to cancer patients typically includes information regarding the illness or symptoms, symptom management, and discussion of treatment options and is one of the most important factors of supportive cancer care across the whole cancer continuum. The goal of providing appropriate information is to prepare the patient for their treatment in order to increase adherence to therapy, to increase their ability to cope with the cancer and to promote recovery (Osborn et al., 2006). In the light of the importance of giving psycho-education to a cancer patient, a previous systematic review has unfortunately showed that between 6-93% of the cancer participants have reported adequate information provision as an unmet need throughout their cancer experience (Husson et al., 2011). As an oncology psychologist, it is important to



understand the new and unknown and threatening world of cancer and cancer treatment and (medical) vocabulary of your cancer patient. Especially with a first diagnosis, the breast cancer patient and her family's life change immediately in a physical and emotional roller-coaster and by just hearing simple descriptions and clarifications about their illness and what to expect, bring a little bit of "safety" and security into this unknown time.

Husson and colleagues (2011) emphasise that giving information to a patient, his/her age, gender, cultural background, educational level, cancer type, stage and coping style must be taken into consideration, for providing information that is consistent with the patients' needs is an important element for the patient's satisfaction and might contribute to her health-related quality of life. In practise it means to give the patient enough time to talk about her (cancer) experience first, especially her emotional experience regarding the diagnosis and to give her a chance to clarify what she already knows about her disease and treatment and what her needs are in terms of the therapeutic process onwards. As a therapist it is important to know that "over-information" can also be harmful, therefore it is essential to let your patient lead you, especially in the beginning of the therapeutic process, as to what and how much information she can accommodate emotionally.

Surbone and colleagues (2013) said that we as cancer therapists need to explain to the patient the unpredictable and uncertain nature of cancer and its consequently existential uncertainty, but also speak of the favourable prognosis and cure rates, long-term sequelae, chronicity and the meaning of survivorship to those patients with early-stage or highly curable cancers. On the other hand, patients with advanced or untreatable or recurrent cancer need to understand their prognosis or relapses, progression and palliative and end-of-life care. This should enable the cancer patients to deal with their future with hope, but also allowing for realistic expectations (Mack & Smith, 2012; Surbone et al., 2013). Information can also make the breast cancer patient aware that from the time of diagnosis some cancers can be successfully treated, but that it will require a lifetime of follow-up and care of potential long-term treatment sequelae for them to achieve and to maintain a good quality of life. This is one of the reasons why early referrals are so important, so that the breast cancer patient can, from the beginning, understand

the process of cancer treatment and survivorship and what it will require of them and their families in terms of chronicity (Osborn et al., 2006; Surbone et al., 2013). Because of the high incidence of cancer related fatigue and depression and the impact that it has on the cancer patient I will briefly discuss psycho-education in relation to this two side-effects of cancer.

- **Psycho-education and fatigue:**

Because fatigue or low-energy levels is one of the most common and incapacitating symptoms of breast cancer and can persist for several months or years after the end of cancer treatment I have included it in this discussion in combination with psycho-education (Brem & Kumar, 2011; Johns et al., 2015) Psycho-educational interventions for fatigue integrate proactive guidance about possible patterns of fatigue during and after treatment as a side-effect of chemotherapy and personalized recommendations for self-management (Berger et al., 2015). Patients who have completed their active treatment and still suffer from tiredness find information about the longevity of fatigue, especially after chemo very helpful and find relief in the fact that there is not necessarily something wrong with them (Berger et al., 2015). This emphasises the importance that when normalising a condition or emotion for a patient and putting it into the right perspective, it lessens their fear and anxiety of not understanding a symptom or condition. If a patient is still busy with treatment (especially chemotherapy) it is important for her to understand her own unique pattern of tiredness, e.g. which day after her chemo session is she the most tired and what time during the day is the worst, so that she can time-manage her day around her fatigue and also involve her family into her “fatigue time-schedule”. Different patients react differently to chemotherapy in terms of their fatigue pattern. The aim of psycho-education with fatigue is to prepare the patient and her family with knowledge about acute and prolonged fatigue and its interference with functioning and possible handling mechanisms (Bardwell, & Ancoli-Israel, 2008).

Berger and colleagues (2015) state that especially progressive muscle relaxation and relaxation breathing, exercise, especially walking, and coping skills training improve both fatigue severity and fatigue related interference during the day. According to Dimeo and colleagues (2008) there are increasing scientific proofs

that exercise can markedly reduce cancer-related fatigue. It is important for the patient to understand that physical activity also increases levels of beta-endorphins and serotonin and increase blood flow and circulation which improves memory function and provides a feeling of general well-being (Dimeo, 2001; Hassan & Amin, 2011). It is important for the cancer patient to always make sure from her oncologist or main physician that it is safe for her to start with an exercise program, even if it is just walking.

- **Psycho education and Depression:**

Studies regarding depression and cancer which specifically recommended psycho-education in combination with any form of behavioural psychotherapy, has demonstrated the benefits of brief forms of psycho-education in preparing patients for cancer treatment (Jacobsen & Jim, 2008; McQuellon, & Danhauer, 2006; Vahdaninia et al., 2010). McQuellon and Danhauer (2006) have developed a very brief psycho-educational program designed to reduce anxiety and depression in patients starting cancer treatment. The intervention must be delivered at the time of the initial consultation with the oncologist (a meeting for 15 to 20 minutes) where the patient can ask any questions and has the opportunity to express concerns and the therapist can offer suggestions on how to cope. McQuellon and Danhauer (2006) found this program very effective due to the reducing of the fear of the unknown of the cancer experience at the beginning of the cancer process. In my opinion, this can only work if the patient is referred immediately after the diagnosis of the breast cancer to give her a change to engage in a psychotherapeutic conversation. I do not agree with the time frame (15 to 20 min), for I have found that such a short sessions (as proposed by this program) is insufficient and unsatisfactory for both the patient and the psychologist. The whole oncology experience is already very fast and time oriented for the patient, especially the sessions with the medical team, therefore the session(s) with the psychologist must be more time friendly (but not longer than an hour) in terms of enough time for the patient to express emotions, ask questions and receive proper feedback in the form of useful information. By acknowledging the cancer patient's fears and anxiety and explaining the "normality" of these emotions patients feel less threatened by their anxious and depressive thoughts and feel that their feelings are validated by being told that their emotional reactions were normal

(Nekolaichuk et al., 2012). Normalisation is seen by Nekolaichuk and colleagues (2012) as a benefit in its own right. It is also important to explain the possibility to the patient that because of the cancer treatment, she can develop depression or anxiety and what the symptoms are to look out for (Berger et al., 2015; Cielito et al., 2012; Jones, 2010; Wong-Kim & Bloom, 2005).

#### **4.4.2.2 Cognitive-behavioural therapy (CBT)**

Being a cognitive and cognitive-behavioural therapist, working with cancer patients in a hospital setup or in practice, I incorporate a variety of approaches which involve multiple components within the structure of CBT such as structured psycho-education, cognitive restructuring, behavioural activation, problem solving and goal setting, communication strategies and emotional support (Hopko et al., 2003; Hopko et al., 2008; Spiegel & Rodrigues, 2008). These specific types of interventions have all been shown to be effective for a variety of cancer patients for reasons of their ease of administration as well as face validity (Armento & Hopko, 2009; Carver, 2005; Golden-Kreutz et al., 2005; McQuellon & Danhauer, 2006; Savard et al., 2005).

Cognitive-behavioural therapy is a short-term, goal oriented, rational and practical type of therapy that can help the patient to change patterns of thinking or behaviour that are causing emotional distress and dysfunction (Beck, Rush, Shaw, & Emery, 1979; Whitaker, Watson, & 2009). CBT is defined as all psychotherapies that include both cognitive restructuring and behavioural activation and is well-researched as a successful therapeutic intervention technique working with patients during the trajectory of the cancer journey (Beltman, Voshaar, & Speckens, 2010; Butler et al., 2006; Dolbeault et al., 2009; Hale, Treharne, & Kitas, 2007; Montel, 2010; Osborne et al., 2006). The findings of most of these researches have supported the effectiveness of CBT and have found positive outcomes for cancer patients especially with depression, anxiety, fatigue and general cancer distress. Various studies have also indicated the long-term effectiveness of CBT and the prevention of relapse (Butler et al., 2006; Espie et al., 2008; Park et al., 2008; Simons, Levine, Lustman, & Murphy, 1984).

Cognitive-behavioural therapy is theoretically based on a cognitive model of interactions among cognition, emotion and behaviour and postulates that

symptoms and dysfunctional behaviours are often cognitively facilitated. In the cognitive model, mood and behaviour are regarded as determined by a person's perception and interpretation of events, which then manifest as a string of automatically generated thoughts. These automatic thoughts have their roots in an underlying network of beliefs or schema (representation). Automatic thoughts that lack validity because they originate from dysfunctional beliefs can cause or intensify psychiatric disorders such as depression and anxiety (Beck, 1970; Beck et al., 1979; Chand & Grossberg 2013; Hofmann & Smits, 2008). The therapeutic process, based on the cognitive theory, consists then of helping the patient become aware of the automatic flow of thoughts when distressed and to identify and modify these dysfunctional thoughts.

Behavioural techniques are used to bring about functional changes in behaviour, regulate emotions and help the cognitive restructuring process. Current theoretical approaches to understand the sources of persistent distress after the diagnosis of cancer share a mutual basis within the cognitive paradigm, which is the view that distress is maintained by the individual's negative appraisal of the illness (Cook et al., 2015). It is important for the cognitive-behavioural therapist to understand the patients' cognitive representation of their cancer and the role of their illness perceptions (including thoughts, ideas and beliefs about their illness) in order to teach the patient various coping skills.

Although disease outcomes might be positively influenced by cognitive-behavioural interventions it is important to take into account that external (environment) and internal (personality) factors may also influence the therapeutic process (Hale et al., 2007; Hulbert-Williams et al., 2011; Travado and Reis, 2013). An element that a therapist must take into consideration when doing cognitive therapy with a cancer patient is the importance of individual differences. People view the world differently and they differ in their emotional and behavioural responses to hardship. A person's experience, perceptions and impact of having an illness might influence the interpretation and reaction to the illness (Carver, 2005; Hulbert-Williams et al., 2011). Individual differences play a significant role in people's quality of life during their cancer treatment and in survivorship. It is important to keep in mind that the quality of life of a cancer survivor is partially a product of the cancer experience self, but also to a degree a product of the

individual's personality. Apart from the role that different personalities play in the application of CBT, the time frame within in the treatment trajectory is also important as to which technique will be suited best. An example of this is in the acute stage, where the patient might still feel traumatized after the cancer diagnosis, the aim of the therapy would be to handle the fear and anxiety first through emotional supportive strategies. This will be followed by psycho-education to explain the procedures to follow, normalizing and accepting of stressful emotions and relaxation and breathing exercises to counteract anxiety (Golden-Kreutz et al., 2005; Mulan, 1985; Hulbert-Williams et al., 2011). After completion of the treatment and the re-entry phase, the focus might be more on cognitive reconstruction of irrational thoughts, coping strategies, acceptance and adaptation to the new status quo and learning to live with the chronicity of cancer (Anderson, 1992; Mullan, 1985). Early intervention can never be over emphasised, for it not only enhance short-term quality of life, but would likely decrease the negative impact of stress in the long term.

- **Cognitive-behavioural therapy as treatment modality for depression and anxiety in breast cancer patients**

The National Comprehensive Cancer Network (NCCN) has developed several clinical practice guidelines for the supportive care of cancer patients and one of their guidelines for cancer patients with depression include the initiation of an antidepressant combined with psychotherapy with or without the concurrent commencement of anxiolytic medication. Psychotherapy is viewed as just as effective as medication in treating depression but is more effective than medication on its own in preventing relapse. For some patients, the combination of psychotherapy and medication will be more beneficial than either treatment on its own. For patients with an anxiety disorder, the initial recommendation is likewise for evaluation, diagnostic studies, and modification of factors potentially contributing to the presenting symptoms (Montel, 2010). Individual CBT, such as problem solving, appears to be useful when working with cancer survivors treating their depression and anxiety (Osborne et al., 2006).

One of the primary goals of short term cognitive-behavioural therapy in patients with an underlying somatic disease (e.g. cancer), is to reduce depressive and

anxiety symptoms (Driessen, Cuijpers, de Maat, Abbass, de Jonghe, & Dekker, 2010). The role of cognitions in the development and maintenance of depressive and anxious symptoms has been acknowledged for more than thirty years and cognitive-based therapies (e.g. cognitive therapy and cognitive-behavioural therapy) are regarded as the gold standard of evidence-based treatment for depression and anxiety in adult cancer patients (Osborn et al., 2006; Steiner, Wagner, Bigatti, & Storniolo, 2014). Because depression and anxiety often coexist, the interventions are similar, with focusing on cognitive-behavioural stress management, progressive muscle relaxation, and deep breathing, cognitive restructuring and interpersonal training (Brem & Kumar, 2011). CBT interventions are based on the supposition that cognitions can be monitored and altered and therefore may facilitate change. Effective management of depression and anxiety may impact outcomes such as fatigue, cognitive functioning and over-all health in adult cancer patients (Osborn et al., 2006).

Recent studies have confirmed that up to 48% of anxious and depressive cancer patients experience frequent, uncontrollable intrusive thoughts (Field, Diego, Pelaez, Deeds, & Delgado, 2012; Morris & Shakespeare-Finch, 2011; Steiner et al., 2014; Whitaker et al., 2009). If a person thinks perseveratively, which means repeating a response after the ending of the original stimulus, about his/her negative feelings and problems and losses, it will further contribute to the development of depression and anxiety (Morris & Shakespeare-Finch, 2011; Osborn et al., 2006). Nolen-Hoeksema and colleagues (2008) use the term 'rumination' to describe perseverating thinking about one's feelings and problems, without being able to control the thoughts. It is possible that a thought may start as unwanted, negative and intrusive but the process of attending to this thought repeatedly is what is defined as rumination and is predictive of the onset or maintaining of depressive symptoms.

In a study done by Montel (2010) regarding breast cancer and associated anxiety, they found that the best technique in treating anxiety in this population was cognitive reframing. The purpose of cognitive reframing is to help the patient to focus away from anticipating the worse and change irrational and dysfunctional thoughts to more realistic thoughts. The aim of this technique is to teach the patient to view a situation from different angles without denying the reality of the

situation. Montel also underlines the importance of relaxation therapy associated to the CBT in the improvement of the patient's anxiety level. The ability to relax when symptoms of anxiety occur gives the patient the confidence that she can take control over her body and that she is able to cope with stressful situations.

- **Mindfulness-based cognitive therapy (MBCT)**

MBCT is a direct and more modern extension of traditional cognitive-behavioural therapy. Mindfulness has been defined as the awareness that emerges through consciously concentrating or paying attention in the present moment without being judgmental in your own awareness (Johns et al., 2015; Kabat-Zinn, 2003). Such present moment awareness lessens worry and rumination of negative and disruptive thoughts, allowing for more flexible and adaptive responses to life's present challenges and more openness to experience feedback about the effectiveness of problem-solving efforts (Luoma & Villatte, 2012).

One of the main aims of mindfulness-based treatment is to improve the emotional well-being of a patient by increasing awareness of how automatic behaviour and cognitive reactions of thoughts, sensations and emotions can cause emotional distress. Patients are encouraged to be in the present and to acknowledge and accept their thoughts, sensations and emotions with an open mind and flexibility (Carlson, Speca, & Segal, 2010; Hofmann, Sawyer, & Fang, 2010). By focusing on the present, rather than pondering on the past or worrying about the future, patients can more effectively deal with life stressors that frequently lead to feelings of anxiety and depression (Hofmann et al., 2010; Kabat-Zinn, 2003). As a therapist, it is important to teach the patient to respond thoughtfully (consciously) rather than automatically (unconsciously) to stressful situations and negative emotions.

It is important to learn the patient to focus their thoughts and emotions and behaviour in the here and now, and not letting their thoughts "wander" off without them bringing (controlling) it back to the present (Carlson et al., 2010; Grossman, & Van Dam, 2011; Mrazek, Smallwood, & Schooler, 2012; Hayes, Luoma, Bond, Masuda, & Lillis, 2006).



Part of practising mindfulness is the notion of acceptance which also forms part of the Acceptance and Commitment Therapy (ACT). From an ACT perspective acceptance is a process of being open to whatever one is experiencing without defence (Hayes et al., 2006; Hofmann et al., 2010). ACT encourage patients to accept (or embrace) negative thoughts and feelings such as guilt and anxiety, rather to eliminate them immediately, learning through that, that acceptance can be an important alternative to avoidance (Hayes et al., 2006; Hofmann et al., 2010). Within traditional cognitive therapy, cognitive restructuring is utilized to challenge the validity of dysfunctional thoughts, but in contrast to cognitive restructuring, ACT uses cognitive diffusion techniques to change the meaning of negative thoughts rather than adjust their content (Deacon, Fawzy, Lickel, & Wolitzky-Taylor, 2011). Cognitive diffusion means that no attempt must be made by the person to change the content or frequency of his/her negative thoughts, but instead, focus on changing how he or she relates to the thoughts, such that thoughts are not taken literally as statements of truth or fact, but rather simply represents verbal activity (Hayes et al., 2006; Hinton & Gaynor, 2010). Hofmann and colleagues (2010) state that instead of changing the negative thoughts immediately, the patient must rather focus on new thoughts which make the patient feel more in control over her thoughts and feelings. Cognitive diffusion empowers patients to develop a more non-judgmental and mindful perspective of themselves and of their environments (Deacon et al., 2011).

It is important for patients to understand that some negative thoughts are realistic and normal in severe emotional situations like cancer and is impossible to not have negative or scary or unhappy thoughts. Patients can learn not to feel guilty about having negative thoughts, or feeling anxious, but rather to accept these thoughts and try to focus on something more acceptable that can make them feel better (Manne, Ostroff, Fox, Grana, & Winkel, 2009).

Another concept of mindfulness-based intervention which forms part of ACT is what is called “decentring”. Decentring is described as a mechanism of mindfulness-based cognitive therapy in which patients learn to view their thoughts as events in their minds rather than necessarily being reflections of reality or accurate self-views (Feldman, Greeson, & Senville, 2010). Decentring means

present focusing and involves taking a non-judgmental and accepting stance regarding thoughts and feelings (Fresco et al., 2007). Working with MBCT, a patient can be taught to identify and acknowledge negative and uncomfortable thoughts, and accept it, rather than over-identify with it and become entrapped in them (Luoma & Villatte, 2012). When you then become so attached or fused to these thoughts, it can become very powerful. It is important for the patient to understand that thoughts are just thoughts without minimizing the emotional impact that thoughts can have or invalidate the factual information often associated with thoughts, for both are valid. The point to make for the patient is that thoughts are only as powerful as you allow them to become. They are only words and pictures that drift through your mind and that you are the one giving meaning and energy to it. Just because you “have a thought,” does not mean that it is the truth or that any action must be taken. When frightful and powerful thoughts pop into your mind, or when you cannot get these thoughts out of your mind, then you apply the principles of mindfulness by acknowledging and accepting the thought(s) but then focus on new and more rational and pleasant thought(s) (Luoma & Villatte, 2012).

### **Search for meaning**

The inevitability of death associated with cancer is often one of the first confrontations that a person has with his or her own mortality. The recognition of one’s imminent death can initiate an existential plight, which is the magnifying of thoughts about one’s existence and the potential for non-existence following a diagnosis of cancer (Lee, 2008; Weisman, & Worden, 1977). Thoughts about one’s mortality and purpose in life following a cancer diagnosis can vary from a normal awareness of one’s existence that does not necessarily result in psychological distress to a more persistent state of discouragement and depression that is characterized by severe and unrelenting feelings of helplessness, hopelessness, isolation and pessimism (Lee, 2008).

With a cancer diagnosis, a person’s belief system that has in the past provided a sense of familiarity, stability and security is now questioned and the goals that a person has set out for the future may no longer appear realistic or achievable. This can then lead to, as current literature calls it, the search for meaning which is a

distressing psychological process in which the individual tries to evaluate the impact of cancer on his or her life and try to understand the world (Lee, 2008). The search for meaning is a process by which cancer patients struggle to retain what is personally meaningful for them when nearly all aspects of their life will be threatened by changes caused by the cancer and its treatment. In an attempt to absorb and understand the reality of cancer, patients then undergo a cognitive process that may entail exposure to recurrent and intrusive thoughts about aspects of the cancer experience and avoidant behaviours when the distress of this exposure becomes overwhelming and relief is needed. Although this cognitive process is psychologically and emotionally difficult and tough it is a necessary process (Creamer, Burgess, & Pattison, 1992; Lee, 2008). The successful completion of the process of searching for meaning occurs when the limitations caused by cancer become integrated into a changed and reorganised life schema that once again provides a sense of order and purpose (Lee et al., 2004, Lee, 2008).

Rapidly emerging empirical evidence is proposing that meaning-making coping is a critical mediator between cancer-related distress and psychological well-being (Lee, 2008). According to Lee, cancer patients often turn to health care professionals to help them make sense of the overwhelming information and thoughts and emotions that confront them during their journey from diagnosis to death and that clinicians are inherently implicated to help the patient make sense of their existential plight or dilemma. Lee (2008) and Taylor (2000) gave practical guidelines to use in therapy helping cancer patients to make sense of the meaning of their lives. They divide this into three tasks during the therapeutic process:

- The first task: encourage patients to tell their story from the diagnosis to the present, especially their immediate and arising thoughts, emotions and actions. Ask what has changed in their lives and what still the same is since their diagnosis. Telling their stories gives them time to express all of their experiences and emotions from the time of diagnosis. The purpose of this is firstly to explain and facilitate emotional expression and the grieving process by acknowledging the losses and seriousness of their situation. The second purpose is to demonstrate that there are still elements of their

lives that they continue to maintain control over and to introduce the idea that positive elements can coexist with negative aspects of their lives.

- The second task: the therapist asks of the patients to carefully think back and identify and describe previous critical situations in their lives and to identify the coping strategies and strengths that were previously used to deal with these challenges. This is to illustrate that they could effectively cope with stress and trauma in the past and have survived up to now and that by using the same strength and coping skills now they will be able to deal with the cancer, or they can either learn new coping skills for the present and new situation if their previous techniques doesn't work.
- The third task: In the final task patients are encouraged to think about how to live life as fully and satisfactory as possible in their current situation. It is important during therapy to help them to identify important life goals and activities and how to achieve it. It also gives them the opportunity to discuss with the therapist their thoughts about their uncertain and unknown future and put it against the background of previous strengths and successes that has allowed them to master past challenges and now also include survival of the cancer experience. If the patient is ready this can be the time for more in-depth discussions about confronting the unknown future which may include not meeting expectations, anxieties, the fear of recurrence, or even plans about death and dying (Lee, 2008). The realization that they may not live as long as they had thought, often serves as a motivation to make more realistic short-term goals given the uncertainty of their future.

Visser and colleagues (2009) together with Halstead and Hull (2001) try to explain the threat to a cancer patients' sense of meaning of life through her struggle with a number of paradoxes. Examples of some of these paradoxes are: 1) Although they still view themselves as healthy, they were diagnosed with a life-threatening illness like breast cancer. 2) They are hopeful about being cured and the future, but are also scared of recurrence of the disease. 3) They found meaning in their belief system, yet it was challenged (and is still being challenged) by the cancer diagnosis. 4) They are looking forward to the future, but dreaded the unpleasant treatment and possible mortality that lay ahead. Many patients suffer from these

fears and uncertainties and they may feel the need for help to deal with these fears and to develop a more positive and realistic perspective.

- **Goal Setting**

Much of a person's sense of identity results from a personal journey which presents goals and rewards in the future. Goals are age dependant and range from being short-term and clear-cut (e.g. to cook dinner or to go to a movie, or to drop the children off at school), to being more long-term and abstract (to become a scientist, or to get married, or buy a house or a car). The most prominent and important goal in an individual's life is that of life itself, together with other, as important goals, such as the desire to maintain the self-image of a healthy person and to continue engaging in a wide range of specific activities and the wish of the patient to live out one's intended future with loved ones (Brennan, 2001; Carver, 2005). Carver's approach to cancer survivorship relies on a view in which individual lives are seen as organized around goals which support the notion in contemporary psychology that human-beings are basically goal-directed by nature (Carver, 2005; Stefanic, Caputi, & Iverson, 2013).

Personal goals are self-defined purposes that provide life with structure, direction, rewards and meaning and is recognised that the successful and continued pursuit of important personal goals is a key source of psychological well-being throughout life. Blocked or disrupted goal pursuit can lead to insufficient motivational structure which can induce distress through feelings of hopelessness that life is pointless which can lead to the development of clinical depression or anxiety (Brandtstädter & Rothermund, 2002; Stefanic et al., 2013; Wrosch, Scheier, Miller, Schulz, & Carver, 2003). Within this framework a diagnosis of breast cancer, its treatment and accompanying side effects and the knowledge of a shortened life-expectancy can represents a threat to the patient's prolonged ability to reach her goals and can lead to a pre-occupation with the loss of goals and aspirations that have shaped one's life (Brandtstädter & Rothermund, 2002; Stefanic et al, 2013; Wrosch et al., 2003).

In the months following a diagnosis of breast cancer, negative cognitions in terms of uncertainty about the future, financial uncertainties, time-consuming treatments,

disruption or loss of work activities, changing in family roles and challenging physical symptoms can all present threats to pursuit and accomplish goals in various life domains (Stefanic et al., 2013). Thompson and colleagues (2013) confirm that goal re-engagement involves identifying a new goal and then committing and pursuing the alternative goal. I found in practise that especially after surgery and during chemotherapy, patients struggle with basic day to day achievement of goals because of acute side-effects like nausea, pain and fatigue. It is often the lack of achieving practical goals (e.g. to go to work every day and to be functional at work, or to run the household as before or when there is small children, to maintain certain tasks) that can make a patient feel incompetent and useless. By explaining the reason(s) why “normal” day to day goals are hard to reach (in terms of specific side-effects and symptoms) already make patients feels less incompetent and useless. Patients also need to understand that if a goal is hard or impossible to achieve, it has to be replaced by a new or altered goal that can be achieved and that often after finishing with cancer treatment, some previous goals can again be implemented and achieved, but that there will be some goals that will be changed in the long run because of permanent changes due to the cancer and cancer treatment. This supports the general concept that the new life circumstances imposed by a cancer diagnosis and its treatment can threaten the pursuit and attainment of an individual's personal goals (Carver, 2005; Stefanic et al., 2013; Thompson Stanton, & Bower, 2013; Wrosc et al., 2003). As a therapist it is imperative to know that women with higher levels of symptom burden would also have higher cancer-related goal interference that is associated with higher levels of distress (Stefanic et al., 2013). It is of much value for the patients to learn to adopt goals that is related to their newly changed life context and in response to the demands posed by a serious and chronic health condition (Carver, 2005). In the beginning (just after the breast cancer diagnosis) new goals are created around the treatments, e.g. to “survive” the surgery, or the first chemo, radiation and side-effects like alopecia and other bodily and emotional changes and you help the patient to implement this alongside the old existing (most often) altered goals.

The process of goal adjustment in cancer patients plays an important role in the reduction of emotional distress and adaptation to a chronic health condition.

Losing or changing goals appears to be a challenging process that may contribute to a sense of loss and can accompany depressive symptoms, especially in patients who are giving up on highly important life goals (Manne et al., 2009; Thompson, Stanton, & Bower 2013). Through this process of goal adjustment, they learn that together with new and changed goals, they will experience difficult emotions that need to be talked about, dealt with and put in proper perspective (Low, Stanton, & Bower, 2008). It is important for the therapist to encourage and facilitate re-engagement in new goals (motivational structure) to help reinstate a sense of purpose for them and to provide opportunities for positive affect that accompanies purposeful striving toward attainable goals (Carver, 2005; Brennan, 2001; Thompson et al., 2013).

- **Coping responses and skills**

Coping is the process of managing internal and external demands which are viewed as challenging and exhausting or exceeding the resources of the individual (Brennan, 2001). Coping can be defined as constantly changing cognitive (thoughts) and behavioural efforts to manage specific internal and/or external demands that are comprehended or perceived as a stressor (Drageset, Lindstrom & Underlid, 2010; Folkman, 2010). A breast cancer diagnosis activates a variety of emotional reactions such as anxiety, uncertainty, hopelessness and despair and places extraordinary demands on the breast cancer patient's coping abilities (Drageset et al., 2010; Landmark, Bohler, Loberg & Wahl 2008). Coping strategies are classified as problem-focused coping behaviour focussed on solving the problem or situations and emotion-focused coping behaviour, focussed at changing the emotional reactions to the problem or situations (Folkman, 2010; Drageset et al., 2010). Coping can be active, which refers to confronting problems and deciding on solutions, or can be passive meaning avoiding the source of the distress (van Oers & Schlebusch, 2013). During primary treatments when patients are dealing with the immediate and acute impact of the diagnosis, treatment decisions and side-effects, the adaptive coping responses are more problem-focused, dealing actively with the immediate demands or the situation (e.g. who will take you to the chemo, what will you do the whole time during the chemo to keep yourself busy, who will look after the household when you are at the chemo,

etc.). Post treatment, when the patients return to their everyday lives, adaptive coping appears to become more introspective and reflective (Park et al., 2008). Coping reactions that lead to engagement in the activities of life (e.g. positive and realistic reframing of the situation, the use of social resources and acceptance) can help to diminish distress later in the process of recovery (Carver, 2005). Although personality type plays an important role in the type of coping reactions, I find that breast cancer patients are often open for suggestions and information to understand their psyche better and to learn new coping skills. Tools of coping as a technique include: identification of irrational or negative thought patterns, (dysfunctional thought patterns), normatively effective coping responses, emotional expression, adaptation and the use of social support and practical activities such as deep muscle relaxation and deep breathing.

Coping with cancer also includes coping with emotional distress. Emotional distress, the sixth vital sign in cancer care, is an important outcome and when severe, it has been associated with reduced treatment compliance and elevated risk of disease progression and death (Conley, Bishop, & Andersen, 2016; Pinquart, & Duberstein, 2010). Adjustment to cancer includes managing emotional distress through attempts to reduce and manage the emotional distress that the cancer causes (Conley et al., 2016). Conley and colleagues (2016) used the term regulating emotional distress. Emotion regulating does not mean that the person replaces negative emotions with positive ones, they still experience negative emotions but instead they adjust the dynamics of each emotion and produce adaptive responses to the environment (Aldao, 2013; Conley et al., 2016). Evidence suggest that active efforts to acknowledge, understand, and express emotions are associated with improved well-being and diminished distress in stressful situations (Austenfeld & Stanton, 2004; Stanton & Low. 2012). Patients need to understand that suppressing emotion-related thoughts and emotions can impair psychological and interpersonal functioning, especially when the suppression is chronic. Hiding emotions is unlikely to help them feel better and can interfere with adjustment. Taking into consideration that there are different personalities, processing and expressing emotions is not effective for everyone under all conditions (Campbell-Sills, Barlow, Brown, & Hoffmann, 2006; Gross & Levenson, 1997; Stanton et al., 2000). Findings from a study done by Stanton and



colleagues (2000) reveal that breast cancer patients' use of coping through emotional expression following primary treatment were associated with a decreasing in distress, an increasing in healthiness and an enhanced self-perceived status. There is also a correlation with attending less medical appointments for morbidities related to cancer and its treatment. In the light of the health benefits of sharing emotions, it is important to create a safe and empathetic therapeutic environment for patients where they can feel encouraged and comfortable sharing their innermost feelings.

The two most frequent occurrences in terms of coping that I see in my practise are coping with uncertainty and coping or dealing with a changing reality, which are both fully described by Folkman (2010), and Nelson (1996).

- **Coping with uncertainty:**

Some of the very first questions according to Folkman (2010) that newly diagnosed cancer patients usually ask are: "Am I in danger?", "Will I die?", "How bad is this?" "How will the treatment affect me?" As a psychologist it is important to go through their questions and give them time to express their emotions. It is also beneficial for patients to understand early in the trajectory of their illness that a big part of this cancer journey is the unknown and uncertainty of the illness, but by knowing and accepting it, they can at least prepare for it without stressing over it the whole time.

Uncertainty is a common experience for women living with breast cancer especially when treatment cannot guarantee disease cure and because of the threat of recurrence. There is a prominent connection between uncertainty and psychological stress and it is safe to say that every stressful situation involves some degree of uncertainty. Learning to live with this uncertainty is part of the challenge the cancer survivor has to face (Greeff, 2008; Nelson, 1996; Wonghongkul, Dechaprom, Phumivichuvate, & Losawatkul, 2006). Uncertainty was found to consist out of three main themes namely, 1) uncertainty because of limited or inadequate information, 2) uncertainty regarding the course and treatment choices related to the cancer and 3) uncertainty related to everyday life and coping with the cancer. It appeared that women with breast cancer experience

moderate to high illness uncertainty upon diagnosis, before surgery and at the beginning of chemotherapy. This uncertainty has been associated with uncertainty of diagnosis, outcome of treatment and the impact of treatment of their life, tolerance of physical and mental distresses caused by treatment, survival rate and perceived life threats (Folkman, 2010; Liao et al., 2008). The experience of uncertainty influences the illness experience, adaptation, quality of life and a sense of hope, therefore is an important factor to take into consideration when treating a breast cancer patient in psychotherapy (Liao et al., 2008).

In the period immediately after receiving the cancer diagnosis, the patient experiences shock and denial, and feels as if the world becomes overwhelming and meaningless and that life makes no sense (Livneh, 2001; Swack, 2008). Patients often say that they felt completely numb and couldn't remember anything that the oncologist (or other medical doctor said) after giving the news of the cancer. Most often the initial response for most patients is to minimize the significance of what they were told or to avoid thinking about it all (denial), but is usually only temporary. Technically speaking, this represents the first stage of the grieving process and enables the patient to survive the trauma (Kübler-Ross, Wessler, & Avioli, 1972; Kübler-Ross & Kessler, 2014). It is important for patients to understand that this reaction (denial) can help them to cope on a daily basis with the cancer and make survival possible by controlling their feelings of grief in dignity. It must be explained to them that denial is nature's way of giving them time to come to terms with a lot of overwhelming emotions in quantities that they can handle (Kübler-Ross & Kessler, 2014). Only later, by accepting the reality of the breast cancer will the healing process begin and denial will begin to fade (Kübler-Ross & Kessler, 2014). Some of the most effective coping skills regarding uncertainty are: Information-seeking, cognitive and emotional distancing, emotional support and expressing emotions:

- Information-seeking: this must be applied with care, for giving too much information too quickly frighten some patients as was found in a study done Drageset and colleagues (2010). The preferred method is a step-by-step process to enable the patient to face reality gradually and facilitate accepting and preparing for what might come. By giving adequate

information (actual facts) in their present situation, the patient can be given a sense of control over her situation and will allow her to process the cancer in a less negative way and avoid dwelling on problems that might arise (Loiselle, Lambert, & Cooke, 2006; Rees & Bath, 2000);

- **Cognitive and emotional distancing:** Focusing and engaging on something positive or activities that require concentration and physical activity is an effective coping strategy that will help the patient to cope with uncertainty. Physical activity, as a way of coping, produce positive emotions, reduce anxiety and offer physical and mental strength (Drageset et al., 2010). Patients who are engaged in their work and receive support and positive responses from their colleagues, (when it is physically possible for them to work) can reduce their anxiety and strengthened their self-confidence by diverting their attention away from their cancer and make them feel in control of something in their lives (American Cancer Association, 2014). Work has the potential to help patients to regain a sense of normalcy, of being valued and of re-integration into society. Therefore work comprises a range of positive consequences for the recovery and the psychological well-being of cancer survivors (Mehnert, 2011). Steiner and colleagues (2004) found that work after cancer is highly desirable from a social and economic perspective but is also associated with enhanced self-esteem and quality of life. Taking control over some aspects of their lives and creating order in the chaos they are experiencing can be understood as a basic adaptive coping strategy (Liao et al., 2008).
- **Expressing emotions:** Sharing emotions can give positive relief for some women (Hack & Degner, 2004; Stanton et al., 2000). Crying, talking and writing could provide a healthy outlet for emotions, helping to keep calm and stopping feelings of depersonalization (Hack & Degner, 2004; Stanton et al., 2000). It is important for patients in therapy to learn and understand that allowing themselves to experience negative emotions and to share it with other people can be a healthy mechanism of coping.

- **Coping with a changing reality:**



When circumstances change with time, previous hopes and expectations may no longer be relevant. An example used by Folkman (2010), is where a cancer patient learns that her course of chemotherapy was not effective and a new treatment with more aversive side effects is required, or that there is no further treatments available, or that the cancer has metastasised, or that there is a recurrence after a period of remission. The patient and her family are now faced with the double challenge of sustaining hope while coping with the changing reality. Although recognizing that matters are not going well might mean giving up hope with respect to what had been, but hope itself is not necessarily nullified. When little can be done to affect a particular outcome, religious faith (for instance) can support hope by giving the patient a sense of ultimate control through the sacred or through affirming beliefs about the sacred such as “God will be at my side”. Individuals who rate high on hope as a trait have the advantage of approaching circumstances with a hopeful disposition that is protective, they also tend to show diminished stress reactivity and more effective emotional-recovery than those low in dispositional hope (Ong, Edwards, & Bergeman, 2006).

Illness has a way of disturbing goals that organize day-to-day choices and behaviour. Because of the illness, patients need to adjust their goals to more practical and achievable goals. For example, the mother with young children would concentrate on resting more and attending and focusing on her own health in order to reinstate her health so that she can resume care of her children (Stein, Folkman, Trabasso, & Richards, 1997; Wrosch et al., 2003). This change in reality might seem simple and logical to the oncology team but in a world where cancer is an unknown phenomenon patients don't necessarily have the knowledge to implement simple interventions. The process of revising goals by letting go of goals that is no longer justifiable or achievable and identifying realistic and meaningful goals that adaptive for coping in the present situations is an important form of meaning-focused coping. This maintains a sense of control creates a new sense of purpose and allows hope that is relevant to the new goals (Folkman, 2010).

- **Hope**

Hope can be defined as a longing for an improvement of a dreaded outcome, has elements of a theological quality along with faith and support and can be seen as a positive goal-related motivational state (Elliott & Olver, 2002; Folkman, 2010; Hammer, Mogensen & Hall, 2009). Hope has been characterized in the literature as having a “being” dimension, an element that is deep inside a person’s self that remains positive whatever happens and represent a pragmatic, goal-setting entity in response to situations (Hammer et al., 2009). In the medical literature, maintaining and restoring hope is seen as an important function of the physician-or oncology team (Folkman, 2010). Hope is viewed as a coping strategy that helps people to endure uncertainty and is future-orientated (Drageset et al., 2010; Stanton, Danoff-Burg, & Huggins, 2002). Folkman (2010) discusses hope from the view of a stress and coping theory and is seen as contextual, meaning-based and dynamic and is vital for people who are coping with a serious and prolonged psychological stress. According to Folkman it is imperative for the cancer patient to understand that hope is not static, but has ups and downs and can at times even be absent. Theoretically, hope provides a counter-balance to interpersonal- and intrapersonal incidents that activates anxiety during periods of uncertainty. In this framework hope (as in faith) or hoping (as in actively focusing on reasons for feeling hopeful) acts as an emotion-focused coping strategy (Folkman, 2010). Hope has a calming effect on a patient (and her family) and can be reinforced by other kinds of emotion-focused coping strategies, for example, distracting activities such as exercising, work, social activities or crafts, such as handwork or gardening.

According Folkman (2010) hope has a very special quality that is important in managing uncertainty over time, for hope allows the patient to hold conflicting expectations simultaneously. An example is on the one hand, the patient knows she has cancer which means there is unpredictable biological and psychological effects, and in worst case scenario, even death, but on the other hand, there is also effective treatments and reliable statistics of survivorship that give the patient necessary hope to survive. In other words you can feel scared, anxious and despair, but also hopeful at the same time. Hope facilitates adaptive problem-focused and emotion-focused coping. Hope can have many different faces, such as “I hope to attend my son’s wedding”, “to maintain my dignity”, “to be at peace

with my God”, “that my children/spouse/family will be o.k. without me”, or “not to suffer in the end.” These desires give definition to the foundation for hope and sustained coping till the very end. Folkman (2010) said it is important to ask questions about what patients hope for in cases where reality is changing and a grave outcome is inevitable.

- **The Process of accepting and adaptation as a coping response according to the cancer survivor adaptation model (CSA)**

According to Livneh (2001) an important goal in therapy, working with a patient with a chronic condition, is active acceptance of the condition, accommodation of both environmental demands and particular personal needs and desires and the integration of these changes (biological and physical) into new and positive reconstruction of the self. Through acceptance comes adaptation, which means the opposite of feelings of helplessness and hopelessness and denial of the condition or its implications. Adaptation refers to the psychological processes that occur over time as the patient and their family cope, learn from and adapt to the multitude of array of changes which have been precipitated by the illness and its treatment. Successful adaptation, according to various authors, is the central component of the cancer survivor adaptation model (CSA) and is considered to be on-going and dynamic throughout cancer survivorship with cognitive evaluation of goals as the specific mechanism of change (Brennan, 2001; Livneh, 2001; Naus et al., 2009). The term adjustment or adaptation suggests the completion of change form one state to another. In the CSA model quality of life outcomes include physical, emotional, spiritual, and cognitive adjustments. These effects constantly feed back into the intrapersonal and interpersonal characteristics of the cancer survivor, preparing for the on-going adaptation process to continue (Livneh, 2001). Brennan (2001) emphasizes that changes and adjustment are not always for the worse, they can also precipitate healthy, personal growth, for a life event crisis can be an opportunity for positive personal growth.

The cancer patient’s personal context of intrapersonal and interpersonal characteristics creates the background in which a cancer diagnosis is experienced. Intrapersonal and interpersonal characteristics include the bio-psycho-social-spiritual factors that define the individual and impact the cancer

experience, containing, but not limited to, specific characteristics of the cancer (e.g. type of cancer, prognosis, treatment and late effects), life stage (and associated world assumptions and goals), overall mental and physical health, personality, social support, coping and spiritual beliefs (Naus et al., 2009). These characteristics influence the survivorship experience and play an integral part in the adaptation process over time in that they are continually adjusted by changes in quality of life outcomes. At each stage of life, the individual's expectations about the world provide a stable lens for perceptions of self, definition of goals and predictions about their future. A traumatic occurrence such as a cancer diagnosis could be expected to alter basic world expectations of personal health and belief in a fair world, influencing both short- and long term goals across many areas and quality of life outcomes. According to Naus and colleagues (2009) better quality of life outcomes were reported for cancer survivors who detached from unreachable goals and moving toward new goal achievement during each chapter of cancer survivorship. Naus and colleagues (2009) explain this in a more practical sense: a trauma, such as a cancer diagnosis, can disrupt the continuity of the self-concept, personal scripts and general belief systems, creating an increased risk of pursuing goals that have become either incompatible or unattainable. So when there is a threat due to changing conditions such as cancer, the individual must generate new goals and modify existing goals in an effort to reduce psychological tension and promote coherence of the self-concept.

In the CSA model adaptation from a cancer patient to a cancer survivor involves the creation of new goals and world assumptions applied within the framework of the personal context and continually influencing quality of life outcomes (Naus et al., 2009). If there is then a reduction in quality of life, because of the cancer or cancer treatment, the cancer survivor can then respond by reassigning priority allowances to their existing goals and making changes in these goal domains. Little and colleagues (2002) said that the best way to accommodate the cancer experience is for the cancer survivor to reconstruct plans and expectations for their future. Cancer patients can learn, during a therapeutic process, that because of all the losses and changes they went through because of their cancer, they can never be the same as before the cancer. They cannot look at themselves and the world the same way as before the cancer. Understanding this and grieving the

losses also helps with healthy adaptation and making peace with your “new” life (Livneh 2001; Little, Paul, Jordens, & Sayers, 2002; Naus et al., 2009). The CSA model also suggests that in addition to psychological interventions designed to promote short-term coping skills and stress relief, that life-long focus must be included. This will help the survivor to redefine goals and priorities through establishing new goals in marginal domains through new interests, new social outlets and new ways to engage in life. Long term interventions designed to reorder lives through goal adaptation and identity change might compliment the more traditional focus on short-term interventions that reduce symptoms of stress during diagnosis and treatment. The CSA model suggests that cancer survivors need to be re-assessed for psychological distress over time as adaptation and subsequent coping are not static and that the oncology team must be aware of this, e.g. a cancer survivor may not experience distress during an earlier stage of survivorship, but might require help in coping with stress or emotions in a later stage (Naus et al., 2009; Little et al., 2002). Successful adaptation is reflected in one’s ability to effectively rebuild and manage both the external and environment, and one’s inner experiences (emotions, cognitions and behaviours) and guarantee the achievement of improved quality of life (Naus et al., 2009; Little et al., 2002). The objective when working in the framework of acceptance is to keep the patient engaged in life by maintaining continued goal commitment (Carver, 2005). Greeff (2008) accentuates the fact that the process of learning to incorporate the illness as part of the “new normal reality” is not an easy task. The CSA model highlights the need for longitudinal research in terms of multiple measurements at critical periods during the cancer trajectory and suggests future directions for research investigations and clinical interventions addressing issues of cancer survivorship (Naus et al., 2009).

#### **4.4.2.3 Therapeutic interventions for women with metastatic cancer**

Metastatic cancer is cancer cells that have broken away from where they first formed, known as the primary cancer, which then spread through the blood or lymph system and form new tumours that are then called metastatic tumours. It usually spread to the brain, bone, liver or lungs and have a median survival time of

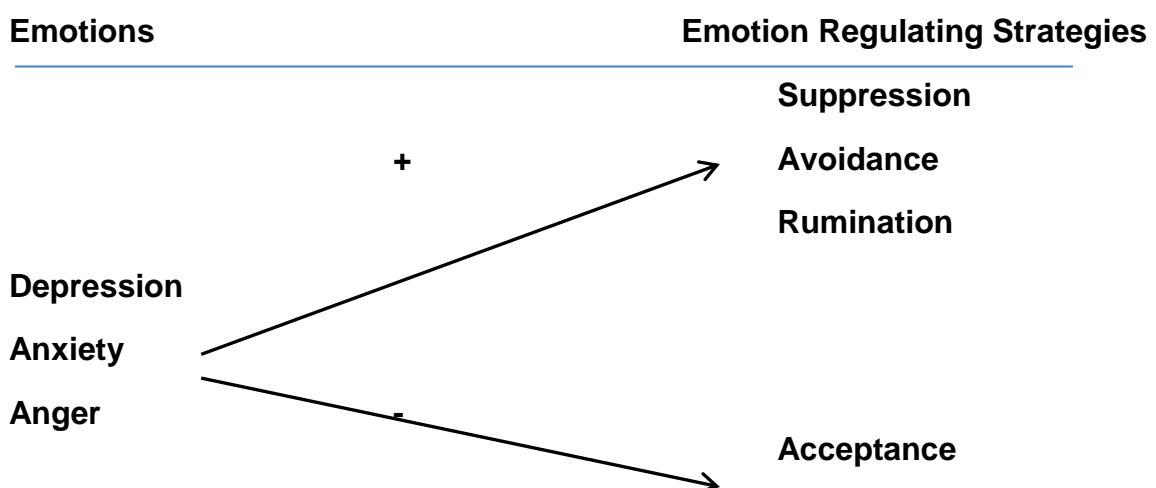


fewer than five years (the American Cancer Society, 2016; Giordano, Buzdar, Smith, Kau, Yang, & Hortobagyi, 2004). Metastatic cancer is associated with several challenges including multiple physical symptoms and progressive physical deterioration that may cause fear and anxiety about the loss of autonomy, death anxiety, dependency on others and the loss of a sense of meaning and purpose. This psychological and social factors together with disease burden have been associated with higher rates of depression and demoralization in this cancer group as opposed to women with less advanced disease (Jacobsen, Davis, & Cella, 2002; Jacobsen & Jim, 2008; Lo et al., 2014). As noted before, psychological distress tends to be more critical in cancer patients with advanced disease, hence the considerable need for psychosocial interventions that is effective against depression in these patients (Jacobson & Jim, 2008; Savard et al., 2005).

Results of studies suggest that short-term cognitive therapy can effectively treat depression in women with metastatic breast cancer in spite of the seriousness of the disease (Jacobsen et al., 2008; Savard et al., 2005). Because of this, systematic screening of depression should be implemented in this population, most probably by the oncologist, who will have the most contact with the patient if she was not referred before (Savard et al., 2005). Thompson and colleagues (2013) has found that depression in this cancer population is often underdiagnosed and insufficiently treated. Savard and co-workers (2005) have adapted a form of cognitive therapy developed for treatment of depression in the general population to meet the needs of patients with metastatic cancer. The goal of this therapy is predominantly to promote a balanced and optimistic but also realistic outlook toward their condition as opposed to either an excessively negative outlook (only thinking of death), or overly positive attitude (just hoping to be cured). The sessions focus largely on helping the patient to modify dysfunctional or irrational thoughts about their cancer and other important situations in their lives. It is important for the therapist working with this population to also acknowledge the fact that in this stage of the illness, there are a lot of natural negative and difficult thoughts and emotions, and that it is not unrealistic to be fearful of death and anxious for those who will stay behind. Thompson and colleagues (2013) feel that it may be more challenging to find alternative goals to pursue when confronting shortened life expectancy and physical limitations. The

ability to adjust goals is especially important when individuals are confronted by prolonged and intense stressors. Understanding the benefits of goal adjustment in the context of serious health conditions may encourage the development of interventions to promote psychological well-being for chronically ill individuals (Wrosch et al., 2003).

It is important for therapists to encourage direct expression of primary negative emotions like fear, anger and sadness in a supportive setting during therapy sessions. This will facilitate solutions of on-going difficulties, release unexpressed emotions and allow patients to adapt healthier thought processes (Giese-Davis et al., 2005). Low and colleagues (2008) found in their study that apart from talking about emotions, writing about it can positively affect a patient's mood. A study done by Giese-Davis and colleagues (2005) (although in group therapy for metastatic cancer patients), the results have shown that emotional expressions in therapy allow patients to be aware of their feelings and cognitions. It gave them time to process their feelings and become aware of choices that they can make that might lessen some of their distress. In contrast, patients' expressions of positive emotions provide information on their own coping strategies. Happiness, for instance could be achieved by choosing circumstances that left patients feeling good, e.g. actively changing inevitable situations such as going to treatment by connecting it to positive occasions junctures like going out on an outing afterwards (Thornton, Levin, Dorfman, Godiwala, Heitzmann, & Andersen, 2014). These authors illustrate in the next figure that suppression of emotional expression or unwanted thoughts can be maladaptive that put patients at risk of heightened emotions and even psychopathology.



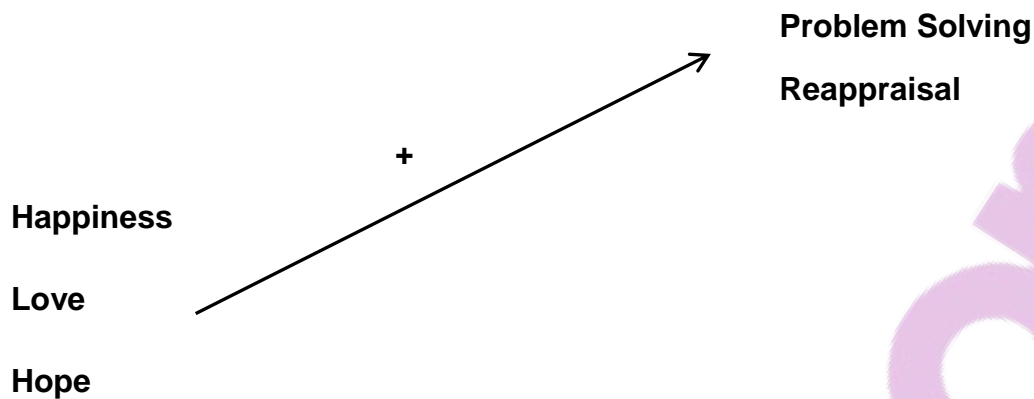


Illustration of emotional regulation strategies by Thornton and colleagues (2014).

Although group therapy for metastatic cancer patients has received substantial attention in the literature with good results, individual psychotherapy is preferred by patients with advanced disease. It creates a safe and supportive environment and is often more practical to deliver, because the sessions can be flexible and can be customised to individual needs (Beacham, Hill, McDermott, O'Brien, & Turner, 2005; Clark, Bostwick, & Rummans, 2003; Giese-Davis et al., 2002; Giese-Davis et al., 2006; Goodwin et al., 2001; Kissane, 2009; Lo et al., 2014; Savard, et al., 2005; Sherman, Pennington, Latif, Farley, Arent, & Simonton, 2007). Lo and colleagues (2014) have designed and standardised a brief psychotherapeutic intervention technique to lessen distress and to promote psychological well-being and growth in patients with metastatic cancer. This intervention relates to the seven elements of Spiegel's therapeutic approach which consists of social support, expression of emotions, detoxifying dying, reordering life's priorities, family support, effective communication and symptom management (Spiegel & Glafkides, 1983). This psychotherapeutic intervention offers support and reflective space for the processing of thoughts and emotions and enables the resolution of practical and existential questions that individuals face with metastatic cancer. Spiegel urged breast cancer patients to reorder their life's priorities to help them take control and enrich the quality of their lives by living beyond the limits that the illness inflicts on them and their families (Spiegel & Glafkides, 1983). Lo and colleagues (2014) named this psychotherapy CALM which stands for managing cancer and living meaningfully. CALM focuses on four main areas that are relevant to patients with advanced disease:

- (a) Symptom control and communication with health care providers.
- (b) Self-concept and relations with close others.
- (c) Spiritual well-being and the values and beliefs that provide meaning and purpose in their lives.
- (d) Preparing for the future, sustaining hope and facing mortality.

Lo and colleagues (2005) feel that managing cancer and living meaningfully (CALM) holds promise as a brief intervention to relieve distress and promote psychological well-being and growth in patients with advanced cancer. It is very important to let your patient understand that even with a terminally, severe illness, that you and others still respect her and that she is worth listening to and that she must still have good thoughts about herself. It is imperative for her to hear that she is not a burden for her loved ones, but a blessing to be able to look after her.

#### **4.4.2.4 Therapeutic interventions with woman with advanced cancer**

Patients with advanced, incurable cancer, face complex physical, psychological, social and spiritual consequences of the disease and its treatment. Care for this population should include an individualised assessment of the patient's needs, goals and inclinations throughout the course of their illness (Peppercorn et al., 2011). Oncology care providers need to recognize the importance of generating an individualised treatment plan for these patients and their families. As a psychologist it is important to initiate potentially difficult conversations with these patients and their families about prognosis, outcomes, options and end-of-life preferences that will fit the patients' need for information and involvement in decision making and establishing a practice model that supports interdisciplinary cooperation around care for this patient population (Peppercorn et al., 2011).

Depressive symptoms that are related to death and dying and other forms of distress, especially fatigue, have been found to negatively affect quality of life, compliance with medical treatment and appropriate health-care application (Berger et al., 2015; Lo et al., 2011; Lo et al., 2014). Although cognitive therapy is an empirically supported treatment for depression in the general population, the effectiveness remains to be demonstrated in patients with advanced cancer, yet according to Savard and colleagues (2005) there are evidence that cognitive therapy showed improvements in depression, mood disturbance, and self-esteem

in this cancer population. While patients near the end of their lives may be focused on life closure and death preparation, those with longer expected survival must be equipped to balance the burdens and anxieties of their illness and approaching death with goals of living in the present, an occurrence that has been termed “double awareness” (Rodin & Zimmermann, 2008).

It is important for the advanced cancer patient in therapy to feel that they still have the capacity to participate in therapy as a worthy person and to be able to learn new and helpful skills that will better their quality of lives and also those of the family. The therapist and patient must take into consideration the physical condition of the patient in order to decide on the types of goals or activities, if it is still possible. It is important that the activities lead to a sense of accomplishment and satisfaction, for instance, to spend more quality time with friends and family. Savard and colleagues (2005) give examples of typical negative and often irrational thoughts such as “I am going to die alone and in pain”, “life is no longer worth living since I know that I am dying”, “I am no longer useful to my family and am just a burden”. The therapist then use cognitive restructuring to modify these dysfunctional or negative cognitions, such as “I know that my family will be there for me till the end”, “my doctor will ensure that I will get sufficient medication to control the pain”, “no one knows how long I am going to live, I might have enough time to achieve some of my goals that are important to me”, “my family are happy to still have met with them”. Because of the advanced stage that the patient might be in, thoughts about fear and death and incapability is not irrational or untrue, and it is important for the patient to know that the therapist is also conscious about this, but that there are still better, more positive and constructive thoughts that will benefit both the patient and her family in terms of their quality of life. Savard and colleagues (2005) said that it is better to set life goals that the patient may not have time to achieve than to have no life goals at all. Only waiting for death makes a patient feel helpless.

During this stage of cancer, specific needs of the family members may arise and may have a major influence on the adjustment of the patient, such that direct contact with, and support of family members is often necessary (Beacham et al., 2005). During this stage it can be beneficial to engage family members of the patient in a therapeutic process to discuss their own emotions and needs

regarding the patient and realistic goals concerning their situation. An example of this is for instance when a family member is planning a wedding, for them to take time (that might be left) and the patient's physical condition into consideration. Family members must be made aware of the impact of certain decisions on them and the potential for regret after the patient's death about things left undone, for instance, if the wedding was planned to late and the mother could not attend, how the daughter would then feel about that. Only through open communication can the family make plans that accommodate the likely course of the disease and make the most of the moment (Beacham et al., 2005).

#### **4.4.2.5 Palliative care in the context of therapeutic interventions**

Palliative means soothing or comforting and palliative care offers specialised treatment to patients whose illness is no longer considered curable. The primary goals of palliative care is to provide comfort and care for those with life-limiting illnesses and their families and to ensure that the patients are able to die peacefully in the setting of their choice, often in their own home, while receiving necessary nursing, medical, psychological and spiritual care (Chochinov, 2006). The world Health Organization (WHO) defines palliative as an approach that improves the quality of life of individuals and their families facing difficulties associated with a life-threatening illness through the prevention and relief of suffering by ways of early identification, assessment and treatment of pain and problems concerning physical, psychosocial and spiritual factors. Palliative care is helping patients live as actively and comfortable as possible until their death, with support being provided to help families cope during their loved ones' illnesses and into their own bereavement (Chochinov, 2006; Singer, Martin, & Kelner, 1999).

Patients confronting a terminal illness who have pre-existing anxiety disorders are at risk for reactivation of their symptoms (Chochinov, 2006; Breitbart, Gibson, & Chochinov, 2005). Symptoms such as pain or weakness may reactivate a generalized anxiety or panic disorder, while patients with a history of phobias especially fear of death, may display anxiety symptoms requiring both medication and emotional support. Patients and their families experience such relief when they understand this type of near death fears and phobias and that the underlying course of these fears are not because the patient is not "ready to die" but because

of a psychiatric predisposing (Chochinov, 2006; Breitbart, Gibson, & Chochinov, 2005).

Weisman (1972) outlines four criteria for what he referred to as an “appropriate death”. 1) Internal conflicts such as fears about loss of control should be reduced as much as possible. 2) The patient’s personal sense of identity should be sustained. 3) Significant relationships should be improved or at least maintained, and if applicable and possible, conflicts resolved. 4) When possible the patient should be encouraged to set and attempt to reach meaningful (albeit limited) goals.

#### **4.4.2.6 Interventions with the family and social support system**

Whatever the actual prognosis of the cancer is, it confronts the patients and those in their social world with the threat of permanent separation from loved ones which is profoundly distressing, not only because of the fear of leaving the world alone, but also because people anticipate the grief reactions of their loved ones. In a cancer world, assumptions about autonomy and dependency within relationships become more obvious. The demands of cancer treatments can also lead to changes in social roles (e.g. where the patient was always the care taker but now are the one to be taken care of) which may challenge established assumptions about self-worth and self-efficacy. Parents with young children in particular, experience intense and invasive fears about the fate of their children in the event of their death therefore the assumed worlds of both the patient and those attached to them require adjustments preferably through psychotherapy (Brennan, 2001).

According to Nicolas (2013) families facing cancer are conceptualized as second-order patients, responding to the strain of cancer as interdependent emotional beings. The diagnosis of cancer of one member of the family has a rippling effect throughout the whole family system; with the primary threat that of separation. This threat may obliterate ideas about autonomy and independency or dependency within a relationship, and the fear of questioning the unspoken dependency needs can lead the couple or family to engage in unhelpful defences such as withdrawal and criticism. Relationships will require considerable adjustments and accommodation over the course of the cancer illness as both the patient and her significant others have to adjust to role changes brought on by the

illness and its treatment (Brennan, 2001). Healthcare systems are not always aware of the impact that the cancer has within the family milieu. Families are launched into an unfamiliar environment where they often have little or no time emotionally and psychologically to absorb and integrate the illness within the average course of their lives. It can happen that the needs of the family members are often neglected because all the attention goes to the patient (Baider, 2008).

It is a well-known fact that healthy and mature relationships among family members offer fundamental social support resources, safeguarding cancer-related stressors. However, even when there are healthy inter-family relationships, a cancer crisis can challenge patterns of family cohesion and adaptability due to concerns, role changes and disruptions to daily routines that come during active cancer treatments. Normal family development can be delayed or disrupted in response to cancer treatments and even after completion of cancer treatments, there might be continues family changes to adapt to a “new normal”. Family rules, boundaries and communication patterns are all challenged by the aftermath of cancer. The threat that cancer poses to the family can be best understood against the background of how different members, individually and as a whole, form and share meaning about specific stressful situations, their identity as a family and their view of the world (Baider et al., 2008; Surbone et al., 2010). It is important to explain to families that neither the patient nor the family can ever return to a pre-illness status quo and that the only way to reach a successful working family functioning is through proper education for everybody about the impact of the illness, in the short-term but also for the future (Baider et al., 2000; Surbone et al., 2010). Providing this emotional contributory support to cancer patients’ families during the entire illness is based on a thorough assessment of their cohesiveness, empathy and support, flexibility and shared needs (Surbone et al., 2010). Both patients and family members can benefit from various forms of psychological intervention. It is imperative to explain to the family the importance to listen and understand the negative feelings of the cancer patient and that acknowledging and expressing negative emotions does not mean that the patient doesn’t feel positive or hopeful, but that it is mere human factor. By allowing the patient to feel and express negative feelings the family will also then allow themselves to acknowledge, accept and work through their own negative feelings (Hack &



Degner, 2004; Stanton et al., 2000; Thornton et al., 2014 Giese-Davis et al., 2005).

#### **4.4.2.7 Pharmacology and psychotherapeutic interventions**

Although a psychologist cannot prescribe any form of medication, it is essential to understand the workings, impacts and benefits that medication can have on your patient, especially in terms of her mood and overall functioning. I will very briefly discuss some of the pain medication and anti-depressants, for it plays a prominent part of the psychological experience of a breast cancer patient.

The National Cancer Control Initiative's (NCCI) guidelines for psychological and social care of adults with cancer recommends that depression can be managed by incorporating a combination of supportive psychotherapy, CBT and pharmacotherapy (Jacobson & Wagner, 2012). The superior value of the combined treatments of psychotherapy and pharmacotherapy in depression in cancer patients over either treatment alone has been confirmed in several meta-analyses (Cuijpers, Dekker, Hollon, & Andersson, 2009; de Maat, Dekker, Schoevers, & de Jonghe, 2006, 2007; Hart et al., 2012). The combination of cognitive- and pharmacotherapy for depression is also widely practiced with good results (Butler, Chapman, & Beck, 2006.) Cuijpers and colleagues (2010) found psychotherapy and pharmacotherapy are about equally effective in treating depression and anxiety within the cancer population, but are more potent in combination with each other than on their own. In a meta-analysis, Fann and colleagues (2008) found that treatment with SSRIs was somewhat more effective than treatment with psychotherapy. One difference that was found between psychotherapy and pharmacotherapy was that although both provided similar efficacy in the short-term, psychotherapy had superior results in the longer term (de Maat et al., 2006; Spielmans et al., 2011).

In treating depression in patients with breast cancer, antidepressants are effective, especially serotonin reuptake inhibitors and norepinephrine reuptake inhibitors combined with cognitive and behavioural therapy. Authors like Frann and colleagues (2008) and Brem and Kumar (2011) believed that this combination might improve the recovery time more than just cognitive treatments alone.

To very briefly explain some anti-depressants:

**SSRIs:** Selective serotonin reuptake inhibitors (SSRIs) are the most commonly prescribed antidepressants because of their relative safety and the fact that they have fewer side effects than some of the other anti-depressants. SSRIs can ease symptoms of moderate to severe depression and anxiety. Serotonin is one of the chemical messengers or neurotransmitters that carry signals between brain cells. SSRIs block the re-absorption or reuptake of serotonin in the brain, making more serotonin available, which then eases the symptoms of depression. Examples of SSRIs that are often used in cancer care are: Citalopram (Celexa), Fluoxetine (Prozac), Paroxetine (Paxil) and Sertraline (Zoloft) (Homberg, Schubert & Gaspar, 2010).

**SNRIs:** Serotonin-norepinephrine reuptake inhibitors (SNRIs) is a class of antidepressant drugs and is used in the treatment of major depressive disorder and other mood disorders, such as anxiety, obsessive-compulsive disorder, chronic neuropathic pain and fibromyalgia syndrome, as well as for the relief of menopausal symptoms. Examples of SNRIs that are often used with the breast cancer population are: Serzone, Cymbalta, Fetzima and Pristiq.

Venlafaxine (Efexor) is a dual serotonin/norepinephrine reuptake inhibitor that has been widely studied in breast cancer patients because of its effects on menopausal symptoms (Homberg et al., 2010; Nemeroff, Entsuah, Benattia, Demitrack, Sloan, & Thase, 2008; Kligman, & 2010; Paice & Ferrell, 2011). A trial done by Loprinzi and colleagues (2000) suggested that Venlafaxine can alleviate hot flashes and that the most appropriate dose for this indication is 75 mg daily and the effect can occur in a few days. Venlafaxine is one of the few anti-depressants that would not necessarily decrease the libido as most of the other anti-depressants do. The anti-epileptic Gabapentin has also been shown to decrease hot flashes to a similar degree and modest improvements in hot flashes have also been recounted for other SSRIs and SNRIs, including Fluoxetine and Sertraline (Henry, Stearns, Flockhart, Hayes, & Riba, 2008).

**Tricyclic antidepressants:** Tricyclic antidepressants (TCAs) act by inhibiting reuptake of norepinephrine and serotonin by blocking the transporters responsible for reuptake of these neurotransmitters. This inhibition elevates the concentration

of neurotransmitters in the synapses and triggers further neurotransmission. Tricyclic antidepressants are used to treat depression, bipolar disorder, anxiety, obsessive-compulsive disorder and other mood disorders. They are also effective as analgesics so are used to treat chronic pain and used for migraine prophylaxis. Examples of Tricyclic antidepressant that are used in this population are: Doxepin, Clomipramine, Amitriptyline, Imipramine, Nortriptyline, Mianserin (Depnon) and doxepin. Tricyclic anti-depressants pose a bigger risk in overdose than SSRIs which may not be a good choice for patients with suicidal ideation (Rayner, Price, Evans, Valsraj, Hotopf, & Higginson, 2011).

To conclude the use of anti-depressants with or without psychotherapy in cancer care is the evidence from a study done by Rayner and co-workers (2011), that depression in patients with a life-threatening illness can be effectively treated with anti-depressants which were superior to placebo.

#### **4.4.2.8 Summary**

Cancer is a disease with varied outcomes including cure, but cancer patients and their families together with the oncology team need to be educated and motivated to move away from the general toxic connotations of cancer to generate a new outlook at cancer care which include the human side along with the biological element. In treating the breast cancer patient comprehensively, the oncology team must acknowledge and incorporate the role of psychological elements and enhance the availability of these services. There is a growing body of evidence supporting the effectiveness of psychological interventions in the treatment of breast cancer patients that can serve as a guide in the practical application of this service and although the central challenge of cancer remains to eliminate the disease, the primary psychological aim is to enhance the quality of life of the breast cancer patient and her family. There is a wide range of approaches to successfully treat a breast cancer patient psychologically, with the most studied that of psycho-education and various forms of Cognitive-Behavioural Therapy. These studies were done in both group settings and individual psycho-therapy with the mutual aim to improve and enrich the psychological well-being of the patient.

Women play essential and influential roles as partners, wives and mothers in the family structure and when she develops breast cancer the whole family are severely affected by her illness. Intervening psychologically as early as possible not only prevents the development of serious psychiatric problems such as depression or anxiety in the patient but also keeps the whole family structure functional through healthy psychological- and social adaptation to the losses and challenges of breast cancer.

## CHAPTER V

# SEX THERAPY AS A PSYCHO-ONCOLOGIC INTERVENTION FOR BREAST CANCER PATIENTS

### 5.1 INTRODUCTION

Sexuality is a deep, enveloping and fundamental part of the total human personality, comprising a person's most intimate feelings of individuality and inspires the complete range of the human experience. Sexuality exists in all interactions and contexts and correlates directly to an individual's overall well-being. It therefore becomes clear that it is not a conception that can be regarded in separation from that of health (Sheppard, & Ely, 2008). According to Hordern and Currow (2003) individuals encountering a life-limiting illness may welcome the opportunity to discuss issues of their intimacy and sexuality with a trusted health professional.

Cancer and cancer treatment, especially chemotherapy can cause changes in the female body and although it may not necessarily interfere with the women's physical ability to have sexual intercourse, it often affects sexual functioning and intimacy and consequently also emotional relationships (Fobair & Spiegel, 2009; Kuo et al., 2008; Sbitti et al., 2011; Taylor et al., 2011). It is widely recognised that a woman's sexuality can be affected in a complex manner after being diagnosed with breast cancer and sexual changes due to the treatment often becomes a problematic aspect in her life. The impact of such changes can last for many years after successful treatment, and can be associated with serious physical and emotional side-effects (Emilee et al., 2011; Speer et al., 2005; Taylor et al., 2011; Usher et al., 2013). In spite of sufficient evidence that many cancer patients would like to discuss their sexual functioning regarding their cancer status, many feel reluctant to do so, partly because of their own discomfort to talk about sex and sexuality, but also because of limited opportunity in the oncology environment (Kuo et al., 2008, Park et al., 2009, Reece et al., 2010). It is important for the breast cancer patient to understand that staying sexually active is an appropriate part of recovery from cancer and its treatment and that there are many effective

treatments for sexual problems and dysfunction, ranging from psychological and behavioural therapy to pharmacological therapy (Fobair & Spiegel, 2009; Park et al., 2009; Schover, 1991).

## **5.2 DEFINITION AND DESCRIPTION OF SEX THERAPY**

Sex therapy can be defined as a therapy which addresses patients' psychological and physical sexual problems and include all relevant methods such as psychological, pharmacological, educational or surgical methods and techniques (Hummel et al., 2015). Sexual dysfunctions can be treated effectively with face-to-face forms of sex therapy and comprises of a flexible program including a number of elements that can be adapted to the needs of the individual patient or couple (Günzler & Berner, 2012). Sex therapy usually includes behavioural components resulting from techniques developed by Masters and Johnson such as psycho-education about sexuality and sexual dysfunctions relating to breast cancer and treatments. Other techniques are sensate exercises, cognitive restructuring of inflexible sexual thoughts and pharmacology (Hummel et al., 2015; Masters & Johnson, 1970; Park et al., 2009).

Although sex therapy can be delivered individually as described in the literature, interventions with stronger outcomes tend to be couple-focused which include treatment elements that educate both partners about the women's breast cancer diagnosis and treatments side-effects on her sexuality. It also promotes couples' mutual coping and support processes and include treatment modalities that make use of specific sex therapy methods that address open sexual communication skills and sexual and body image concerns (Hummel et al., 2015).

## **5.3 AIMS AND BENEFITS OF SEX THERAPY**

In working with breast cancer patients, it is important to initiate conversations about sexual functioning whether it is in the medical setting with the oncologist or surgeon or with a psychologist (Park et al., 2009). If the conversation about sexual functioning is with the medical team, then the ideal would be for the oncologist or the surgeon to refer the patient from a very early stage to a psychologist working with this type of issues or dysfunctions. It is imperative that conversations regarding sexual functioning and cancer become an integral part of cancer care.

Discussing sexual functioning with cancer patients can help normalizing their concerns about their sexuality and provide a foundation for (brief) sexual therapy if it is later necessary (Park et al., 2009). One of benefits of early conversations with patients about their sex lives and intimacy is for them to feel comfortable speaking about their sexual well-being or problems and to realise that it is acceptable to talk about sex and sexuality and that there are applicable interventions for this problems. It is important for psycho-therapists to explain to their cancer patients that they can expect changes in the way their bodies are going to react and respond to sexual encounters during and after chemotherapy and that these changes could affect their sexual and intimate relationship with their partners (Fobair et al., 2006; Fobair & Spiegel, 2009). In a study done by Park and colleagues (2009) they have found that most of their participants wanted basic information about their sexual functioning and assurance that their sexual changes are normal in their specific situation and that other patients also experience the same challenges. Many of these participants reported back that they were not properly prepared for sexual changes or equipped to cope with it.

An important aim with sex therapy in the oncology framework is to remove the barriers in sexual health communication between the oncology team and the breast cancer patient. According to several authors sexual issues are not yet sufficiently integrated into routine cancer care and that health professionals must aim to integrate patient sexuality and intimacy into routine palliative assessments so that every patient is given the opportunity to discover these matters (Hordern & Currow, 2003; Hummel et al., 2015; Park, et al., 2009). Park and colleagues (2009) found that breast cancer patients showed a desire to have open communication and frank discussions about their sexual issues with the medical professionals and they wanted “permission” to discuss their sexual concerns with their medical team. Communication about sexuality can be tough and challenging for the oncologists because they often lack time and knowledge to attend to the sexual matters of their patients despite the patients’ needs and requests to talk about their sexual functioning during the course of their cancer treatment (Hordern & Currow, 2003; Park et al., 2009).



If patients are referred to a psychologist early in their breast cancer treatment, discussions about their sexual well-being can start early on in the therapeutic process to prepare them for potential changes in their sexual functioning and prevent the development of unnecessary and serious sexual pathology. It is helpful for the cancer patient to hear from the oncologist or psychologist that there are not just sexual side effects due to the cancer treatment, like low libido, vaginal dryness and menopausal symptoms, but also available interventions to treat these sexual symptoms. It is important to counsel patients when appropriate, that sexual activity is not harmful, but can be an integral part of the recovery process (Fobair & Spiegel, 2009; Taylor et al., 2011). Prior knowledge of treatment-related sexual side effects could help patients to make better informed decisions about treatment options and the practical information can help patients with their sexual expectations in the future (Park et al., 2009) This information should also be repeated at various times during the therapeutic process to make sure that the patient stays in contact with her sexual functioning throughout the trajectory of her cancer journey. Sex therapy teaches patients to acknowledge their sexual changes and challenges and to develop new skills to enhance their sex lives and intimate relationships (Jun et al., 2011).

#### **5.4 SPECIFIC INTERVENTIONS IN SEX THERAPY PRACTICE**

For Schover and colleagues (1984) sexual rehabilitation should begin at a very early stage of the breast cancer treatment plan for although the patients might still be concerned with life-and-death issues, they will also start thinking about the quality of their life during the treatment process. By participating in sex therapy from an early start, the breast cancer patient can continue to feel sexually attractive and functional and will be able to sustain and conserve better courage and self-esteem throughout this process. Schover and colleagues (1984) feel very strongly that withholding information about sexuality is never justifiable and that, because of the lack of information, patients spend hours needlessly wondering whether they will still be able to feel sexual pleasure or whether their partner will be forced to look elsewhere for sexual satisfaction. It is important to communicate to the patient that sexual pleasure and activity can continue (if the patient wishes) throughout the treatment and thereafter.



It has been suggested in the literature that many breast cancer patients and their partners can benefit from brief sex therapy. Such sex therapy can include components such as cognitive and behavioural coping skills, psycho-education on how the cancer treatment can impact their sexual functioning, proposals on how to resume sex without anxiety and performance-anxiety and facilitating skills to improve sexual communication. Sex therapy can also include the handling of specific sexual problems such as loss of sexual self-esteem, pain, loss of desire, fatigue and menopause (Derogatis & Kourlesis, 1981; Fobair & Spiegel, 2009; Hughes, 2008; Masters & Johnson, 1970; Schover, 1991). Hughes (2008) agrees with authors like Derogatis & Kourlesis (1981) and Park and colleagues (2009) that sometimes sympathetic understanding of the patient's problem and careful evaluation of her concerns may already be in themselves therapeutic. They all agree that for any sexual dysfunction it is important to treat both the physical- and psychological conditions and that anxiety and depression as well as physiologic symptoms can be treated with medications and or psychotherapy which can include cognitive-, behavioural-, marital- or sexual therapy. A theoretical framework for sexual interventions for this study was derived from three different sexual intervention models which all falls into the bio-psycho-social framework for therapeutic interventions and will be discussed separately. The three models include the Five A's comprehensive model, the Masters and Johnson's model of sensate focusing and flexibility as a model of sexual intervention for patients with chronic illness:

#### 5.4.1 The five A's comprehensive model

Park and colleagues (2009) has developed a comprehensive model working with sexual problems in the cancer population. This model relies on a multidisciplinary approach where different clinicians may take on different components of the 5 A's. It offers a very basic and practical framework to use especially at the beginning of therapy to initiate either sexual "conversation" or sex therapy. This model consists of the next components:

- (a) ASK: The first task in this model is to "ask" by simply bringing up the topic of sexuality. It is important for the oncologist or psychologist to understand that the patient sometimes need to receive information about their sexual,

anatomical and physiological functioning to help them understand how sexual side effects are connected to their cancer treatment. A conversation about sexuality from the oncologist or psychologist will give the patient the opportunity and confidence to discuss any questions regarding their sexual functioning and their illness. All adult patients, regardless of their age, marital status or whether they are receiving palliative care, should be asked about their sexual issues throughout the whole trajectory of their illness and treatment (Park et al., 2009). The goals of such a discussion are to provide accurate information in practical terms for the patients to understand their situation and to help them to come to terms with their feelings about sexuality and cancer (Schover et al., 1984). Depending on the multidisciplinary team's composition, this will be asked either by the oncologist just to open the subject or from the beginning by the psychologist for it will ultimately be part of their therapeutic route. If a breast cancer patient is referred for psychotherapy, regardless of the reason, it is important to mention the influence of cancer treatment on sexuality and that speaking about it can be part of the therapeutic process. The comfort displayed by the therapist in addressing sexual functioning with confidence and authority and without using excessive medical terminology, can create an atmosphere of comfort and safety where the patient or couple can express their sexual concerns without feeling embarrassed (Fobair & Spiegel, 2009; Nusbaum et al., 2003; Park et al., 2009).

- (b) **ADVICE:** This step provides an opportunity to deliver a brief, dynamic message about the importance of sexual problems in the cancer treatment regime such as low libido, decreased sexual self-image, vaginal dryness, dyspareunia and menopausal symptoms and the role it can play in the overall quality of life. This is also the time to normalize sexual and intimacy experiences and symptoms for the patient through acknowledging the fact that many cancer patients struggle with sexual problems and even dysfunctions during and after their cancer treatment. During this time the therapist can reinforce the fact that sexual functioning is an important quality of life issue and to reassure patients that they can get help if they

suffer from sexual problems in the form of marital therapy, individual- or sex therapies (Fobair & Spiegel, 2009).

- (c) **ASSESS:** According to Park and colleagues (2009) professionals may find it easier to begin the process of sexual interventions by asking their patients about their sexual symptoms to initiate dialogue about sexual problems and treatment recommendations. Sexual rehabilitation, according to Schover and colleagues (1984) begins with the least anxiety-provoking questions, e.g. “Are you still sexually active together?” “How often do you have sexual activity?” The assessment should then progress to questions about each aspect of the patient’s sexual functioning including desire (libido), arousal (vaginal lubrication, subjective pleasure), orgasm (quality of sensation, type of stimulation needed), pain during sexual activity (including non-genital and genital discomfort) and satisfaction of each partner with the frequency and variety of sex. Sexual communication and information about how the patient feels about herself as a sexual person (sexual-esteem) is also an important aspect to assess. It is important to ask when the problems have begun, in what context did they first experience the problem or problems and how long have they lasted (Derogatis & Kourlesis, 1981). Seeing the patient and partner together will allow the therapist to assess the effectiveness of the couple’s general communication, especially their ability to discuss sexual concerns and often the therapist gets a different picture of the quality of sexual performance after speaking to the patients’ partner (Derogatis & Kourlesis, 1981; Nusbaum et al., 2003). Nusbaum and colleagues (2003) suggest that in taking the sexual history, although the inquiry should be sensitive, it must also be direct enough to clarify the issues at hand. Obtaining a detailed sexual history is not only important in addressing appropriate sexual matters, but the catharsis is therapeutic in itself (Derzko et al., 2007).

What is important in asking for the sexual history is to establish a sexual frequency baseline and estimation of the patient’s previous sexual interest, it is also important to verify whether the patient has ever (before the cancer) experienced sexual dysfunction and if so, what was the nature of the

problem and if she underwent any kind of treatment. If there is a current sexual problem then more time should be spent asking about the patient's sexual attitudes and experiences and if possible, in a developmental framework for it is already established that the younger the patient, the bigger the probability of sexual problems (Burwell, Case, Kaelin, & Avis, 2006; Fobair et al, 2006; Fobair & Spiegel, 2009). Furthermore, the sexual history should also be taken in the context of the current medication and stage of the cancer treatment, for certain cancer treatments and reduced hormone levels may result in lowered mood, fatigue and loss of sexual interest, not just because of biological impacts but also because of a possible reduction in sexual satisfaction as a result of dyspareunia or other gynaecological effects of cancer treatment (Derzko et al., 2007). With the information of the sexual history, the clinician should have an understanding of the patient's typical levels of sexual performance and her perception of her own sexuality, for example whether she is sexually conservative or liberal. These issues can become important when the cancer or treatment either temporarily or permanently precludes sexual intercourse in the usual manner and alternatives must be created and implemented, e.g. alternatives that would be perfectly acceptable to a more liberal patient, but might be viewed as perverse and totally unacceptable to a more conservative individual. In assessing the nature of a sexual problem it is critical to determine precisely what physical changes the patient's body has withstood because of the cancer or treatment and the options left open by the cancer. The patient's current psychological status must also be contemplated so that dysfunctions associated with clinical levels of depression or anxiety is recognized as such and taken into consideration when planning for the treatment. One of the more difficult decisions to make is to determine if the sexual dysfunction is mostly biological or psychological in nature, but often both factors may be working together, for example: dyspareunia resulting from a post-surgical stenosis resulting in an anorgasmia based on the patient's belief that she is now scarred and mutilated and no longer physically attractive to her partner.

The patient's impressions about the cause or etiology of the sexual problems are also important, especially to establish whether she feels that

in some way she is responsible for the problem and have guilt feelings about it. If the patient says that their sexual functioning is unaffected, it is still necessary to determine if her interest in sex remains high because there might be a problem of desire rather than performance (Derogatis & Kourlesis, 1981).

- (d) ASSIST: On the basis of the assessment of the current sexual functioning of the cancer patient a treatment plan can now be formulated and implemented that will benefit the patient the most. Patients should be informed about available therapeutic options e.g. psycho-education, or cognitive-behavioural techniques or even pharmacology to treat their problem (Fobair & Spiegel, 2009; Hughes et al., 2011; Hummel et al., 2015; Krychman & Katz, 2012). Derogatis and Kourlesis (1981) said that in their experience many sexual problems can be solved by just the opportunity to discuss it in a safe and professional environment. According to these authors a large percentage of patients only need education and basic information about their situation and what they can use safely such as lubricants, vaginal moisturizers, dilators, etc. Other patients will benefit from short-term therapy by a psychologist working with sexual disorders accentuating strategies such as acceptance, education about treatment-related sexual problems, encouraging open sexual communication between partners, encouraging patients to resume sex during and after treatment and learning of new skills concerning sexual performance.
- (e) ARRANGE FOLLOW-UPS: The last step in this 5 Step comprehensive model is to make sure that patients receive follow-ups to evaluate their progress and how they are doing with their sexual well-being. This will reinforce the importance of sexual welfare for the patient and reassure her that it is an issue that she can discuss any time the need may arise. Therapeutic feedback is always important in a healing process.

Derogatis and Kourlesis (1981) summarised this model by saying that regardless of how the sexual problems present themselves or how it get addressed, the most fundamental step that the oncology medical team must make is to accept sexuality as an integral and natural aspect of being human and that the treating team

should work to treat problems arising in this area with the same excellence and commitment that they are devoting to other aspects of cancer care.

#### **5.4.2 Masters and Johnson's model of sensate focusing**

Sensate focusing was developed by Virginia Johnson and became the centrepiece of Masters and Johnson's therapeutic work. It is a hierarchy of consistent, structured touching and discovery through which partners gradually reintroduce the continuous phases of sexual contact (Masters & Johnson, 1970; Weiner & Avery-Clark, 2014). The exercises are aimed at becoming more comfortable with one's own body and achieving sexual intimacy with one's partner, both physically and emotionally. Other goals are to discover new approaches to sexual stimulation, and to encourage communication between partners about sexual experiences, sexual desires and sexual boundaries (Hummel et al., 2015). Sensate focusing is a tool for identifying psychological and relationship factors that contribute to sexual difficulties and for teaching new skills to overcome these problems and to promote a more meaningful sexual intimacy (Weiner & Avery-Clark, 2014).

Working with patients with sexual dysfunctions, Masters and Johnson (1970) have developed and advocated a homework project to change a patient's mental focus from their physical performance back to pleasurable sensations experienced during physical intimacy with a partner. Sensate focus is not so much about behaviour as it is a focus attention attitude. Weiner & Avery-Clark (2013) found that patients with sexual problems were often trying to make sex happen or trying to keep it from happening by touching for their partners' arousal and pleasure and not for themselves, therefore creating performance anxieties. An important goal of sensate focus therapy is to counteract these invalid pressures that a patient put upon herself/himself. The rationale for sensate focus sessions are to regain a sense of awareness of what feels good about being touched and nurtured. Patients learn to focus on receiving physical pleasure and in the absence of expectations of sexual performance, he/she would return to experiencing sexual arousal and interest as a natural result (Weiner, 2011; Weiner & Avery-Clark, 2014; Wiederman, 2001). The two phases of sensate focusing are:

- **Phase I:** Touching for one's interest is what is referred to as Sensate Focus Phase I. This phase prescribes specific suggestions: To start the exercise the couple must set aside enough time to engage in nude, full-body massage where each partner take turns pleasuring the other with the specification that there were not to be any sexual episodes or any sexual activity. The "toucher" begins by touching the partner head to toe, front to back, avoiding the breast, chest and genital areas which are off limits for the beginning. This touching involves only the use of hands and fingers but not full body contact or kissing. This exercise is aimed at reducing any expectation of a sexual encounter. The toucher and the touchee (the person being touched) touch and feel only for themselves with the intention of taking in concrete, tangible and physical sensations such as temperature (cool or warm), pressure (hard or soft) and texture (smooth or rough). If there are any distractions, the participants must make an effort to refocus on the tactile sensations again. If anything is uncomfortable for the touchee, he/she must communicate by moving the toucher's hand away to a place that is more comfortable. There are no limits in terms of the length of time in this touching exercise but the toucher touch long enough to become skilful at focusing (or refocusing) on sensations but not so long that he/she gets bored or tired. When the toucher is finished she/he then say "switch" and then they exchange positions where the second partner touches and the first partner becomes the touchee (Weiner & Avery-Clark, 2014). The advantage of this attitude of touch or being touched for themselves is only taking in their own sensations, they don't evaluate, just experience and only stay in objectivity and encourage exploration and experimentation. Sensate focusing is not about touching for the other person, it is not about touching to sexually arouse one's self or one's partner, it is intended to be an experience in itself. Sensate focusing is not an introduction to sex, neither a form of foreplay, but a paradox of pleasure and sexual responsiveness that being present to conscious sensory experience rather than trying to make these natural emotions happen, is what stimulates them (Masters and Johnson, 1970; Weiner & Avery-Clark, 2014). These exercises are a way for the couple to explore each other's bodies using all of their senses (sight, touch, taste, smell and sound) without focusing on the genitals. The

importance of patience and taking time should be stressed (Hughes, 2008). The advantage of this approach is that when patients are having difficulty responding sexually, they are presented with something reliable (sensations) on which they can focus, as well as an activity over which they have control (refocusing of attention), instead of depending on something unreliable as in emotions and trying to oblige a response over which they don't have a direct voluntary control (sexual arousal).

- **Sensate Focus Phase 2:** This phase concentrate on bigger responsiveness to partner feedback and to emotional experience. When the couple has successfully completed phase 1 of sensate focus and they want to have sex, they can progress to sexual intercourse. Before they go over to intercourse the couple has to understand that sexual desire can vary and is not necessarily synchronous and that the sexual need and desire do not have to be present at the beginning of the sexual activity, for desire can emerge as the individual relax and begin to experience pleasure form intimate touch (Weeks & Gambescia, 2009). As with phase 1, depending on the sexual problems and needs from the couple, they explore. They can take their time and explore with penetration until they are comfortable with it. There are different degrees of penetration, e.g. penetration without thrusting, or penetration with thrusting, penetration with or without orgasm. During phase 2, the therapist will instruct the couple to focus on their sensations (as was learned in phase 1), positive thoughts and fantasies that make the sexual experience pleasurable (Weeks & Gambescia, 2009). This phase also emphasizes that partner communication about their emotional experiences are critical to the longer-term goals of intimacy and optimum sexuality. Masters and Johnson (as cited in Weiner & Avery-Clark, 2014) said that it must be presumed that if there is a lack of effective non-verbal communication in the bedroom, there are probably difficulties with verbal communication outside of the bedroom as well. Therefore it is important for the sex therapist to teach the arts of non-verbal and verbal communication to sexually dysfunctional couples as an essential part of this therapeutic format.



The most important aims of sensate exercise are that the couple become more comfortable with their own bodies and attaining sexual intimacy with their partner, both physically and emotionally and gradually reintroduce the consecutive phases of sexual contact. The other goals are to discover and learn new techniques of sexual stimulation and to teach and encourage communication between partners about their sexual experiences, sexual desires and boundaries. These behavioural elements of sex therapy are usually combined with cognitive therapy where the therapist and the patient aim to detect and change dysfunctional and irrational cognitions regarding sexuality that has arisen during the sensate exercises (Hummel et al., 2015; Ussher et al., 2013).

#### **5.4.3 Flexibility as a model of sexual intervention for patients with chronic illness**

The flexibility model has predominantly been developed from a bio-psycho-social model with the emphasis to change the patient's cognitive perception of sex and sexuality and accompanied behaviour. Up to recent years the dominant model used in understanding the aetiology of sexual dysfunction among patients with a chronic illness was biological where sexual dysfunction is hypothesized as originating from physiological origins of the disease or its treatment. Based largely on biological models, studies of interventions in managing sexual dysfunction among patients' with chronic disease have focused almost exclusively on medical or pharmacological treatment. But because of the limitations of these treatment modalities and the added knowledge and acknowledgement of the role that psychosocial factors play in the aetiology and maintenance of sexual dysfunction, there has been a rising interest in the development of an alternative bio-psycho-social approach.

This approach integrates contextual and relationship factors in the treatment of sexual dysfunctions in the chronic illness population (Barsky et al., 2006). In the view of the complexity of female sexual dysfunctions and the irreversible nature of sexual dysfunction among patients with a chronic illness such as cancer, a bio-psycho-social approach for the assessment and management of sexual dysfunctions with interventions ranging from education and lifestyle changes to sexual therapy, sexual aids, medications and exercises and dietary supplements

is necessary (Barsky et al., 2006; Derzko et al., 2009; Hughes et al., 2011). This treatment model aligns with my own use of the principles of Engle's' bio-psycho-social model which is practical and applicable in treating cancer patients' sexual problems. In developing the flexibility model the focus was on the concept of flexibility in cognitive and behavioural coping. Prior research supports the proposal that flexible coping has beneficial effects for individuals reacting to stressful situations, including beneficial effects on sexual contentment in responding to cancer-related sexual distress (Barsky et al., 2006; Reece et al., 2010). Although the clinical methodology to further flexible coping is heavily educated by previous clinical approaches to sexual dysfunctions in sex- and marital therapy (e.g. sensate focus exercises) the concept of flexible coping also adds to prior approaches in several ways. First, if focusing on the concept of flexibility in coping with sexual matters, it may facilitate a more targeted approach than sex therapy in general which is particularly helpful when considering the (often) brief length of time allowed for providers to confront side effects of cancer treatments and other quality of life issues. Secondly, in the context of sexual counselling or sex therapy, the flexible coping model can address sexual matters due to cancer from different contexts such as psycho-education, cognitive and behaviour mind shift in terms of their sexual functioning, sexual communication skills and emotional understanding and support. Thirdly, because of the nature of the flexible coping theory as consisting of multiple concepts of sexuality, it may reflect a patient's own developing perceptions of their sexuality through their cancer trajectory (Reece et al., 2010). When assessing sexual functioning during the therapeutic process with cancer patients, assessment of flexible coping is necessary and can be done by asking targeted questions. Sufficient assessment of flexible coping should focus on simple questions relating to broader sense of intimacy in addition to sexual performance, for instance, by asking questions related to the patients' sexuality and intimacy, rather than about sexual performance, the therapist is validating the importance of such concerns. Flexible coping may be applicable to any person coping with sexual difficulties as a threat to their sexual lives, irrespective of the person's age, marital status, sexual preference, and level of disease or any other relevant demographic and medical characteristics.

Flexibility can be defined as the ability to shift cognitive or behavioural focus in order to manage acute and chronic sexual dysfunction and is a significant determinant of successful coping with long-term dysfunctions (Barsky et al., 2006). This flexible coping model classifies two potential areas of response that can be altered to be more flexible in response to sexual matters: Firstly, the definition of sexual function and activity and secondly, the significance of sexual function and activity (e.g. how important sexual functioning and activity are for the patient and her partner's overall self-concepts). An example of a person with an inflexible definition of sexual function and activity may believe that sexual activity is synonymous with sexual intercourse and when incapable to engage in sexual intercourse due to illness, this person may experience this challenge or stressor as being at odds with his/her capacity to be sexual and may approach the problem with avoidance of intimacy. Therefore both cognitive changes (e.g. thinking differently about his/her sexual function and activity) and behavioural changes (e.g. engaging in different sexual activities such as alternative forms of sexual activities, including oral sex or mutual caressing) will institute changes in a persons' definition of sexual function and activity (Barsky et al., 2006; Reece et al., 2010). The flexible model propose that greater flexibility as indicated in broader and less rigid thoughts and behaviours (as shown in Table 5.1 and 5.2) will reflect in a more beneficial judgment of the challenge that will likely lead to more effective coping strategies, which will in turn lead to positive psychological outcomes (e.g. increased sexual and relationship satisfaction and mood). Within the model of flexibility a patient with cancer may best cope by shifting both the cognitive and behavioural manifestations of what constitutes sexual functioning.

Barsky and colleagues (2006) explain flexible and inflexible coping in the definition of sexual function and activity in cancer making use of practical examples. As shown in Table 5.1 a patient with a flexible definition of sexual function and activity interpret sexual intercourse, non-sexual activities and non-sexual intimacy activities as part of sexual activity and is likely to see challenges as being more easily overcome and is likely to cope more successfully with challenges such as the person that limit the inability to engage in intercourse. A treatment method applying the flexible coping theory might focus on the patient's ability to move from

an inflexible to a flexible definition of sexual function and activity which involves contemplating a wider range of sexual- and non-sexual intimacy activities.

**Table 5.1: Flexible and inflexible thoughts regarding the definition of sexual function (Barsky et al., 2006).**

Stage in coping process	Inflexible thought	Flexible thought
Cognition	Intercourse is the only real form of sexual activity that counts.” “Cancer has ruined our sex life. We won’t be able to have sex again.	Cancer has changed our sexual relationship, but we can still have a good sex life, just in different ways than before”.
Behaviour	Abstention from any sexual activity.	Engaging in mutual non-sexual activities, masturbation or oral sex.
Psychological outcomes	Negative or depressed mood, poor sexual functioning. Impaired relationship functioning.	Positive mood, enhanced sexual functioning. Enhanced relationship functioning.

In table 5.2 it is shown that a patient with flexible thoughts in terms of the centrality of his/her sexual functioning, may engage in alternative forms of sexual activities through different behaviours, including oral sex or “outercourse” (which is rubbing of the genital outside the vagina), mutual caressing when intercourse is not possible or uncomfortable. Suggesting a change of scenery, for example engaging in sexual activity in the bath or shower or any other place but the bedroom, can also be erotic and a novelty and the patients can broaden their sexual horizons. By shifting cognitive processes in response to sexual dysfunction will have a beneficial effect on psychological well-being and mood and can result in an enhanced experience of sexual pleasure and satisfaction (Barsky et al., 2006; Reece et al., 2010; Schover, 1988; Week & Gambescia, 2009).

**Table 5.2: Practical examples of stages of inflexible and flexible coping in the centrality of sexual functioning (Barsky et al., 2006).**

Stage in coping process	Inflexible thought	Flexible thought
Cognition	<p>“Nothing could replace Intercourse in our relationship anyway”.</p> <p>“If we could go back to having sex like we did before the cancer and treatment.</p>	<p>“Intimacy is a better focus for us now than sex”.</p> <p>“We show our intimacy through laughs and enjoying time together”.</p>
Behaviour	Avoiding intimacy in Relationship.	Enrolling in dancing lessons together and scheduling weekly date nights.
Psychological outcomes	Negative mood and poor relationship.	Positive mood and relationship functioning.

Ussher and colleagues (2013) consider that renegotiation of sex outside the coital obligation involves the positioning of intimacy as more important than sex, including versions of cuddling, kissing, non-genital touching, massage, spending time together and caring or talking. Renegotiating sex and intimacy can also serve to maintain normality in the face of cancer, reassuring the patient that there is still a life away from cancer and “healthy” activities to participate in. Previous research supported the need for sexual information at various stages along the cancer route. Having specific conversations regarding flexible coping with patients may be important at all stages along this trajectory concerning a comprehensive treatment plan (Barsky et al., 2006; Park et al., 2009).

Early Stage: A discussion of flexibility in coping with sexual matters early in the treatment decision-making process, such as “can you imagine having a fulfilling sexual relationship without sexual intercourse being a part of it”, can help patients to consider their own preferences and values with objective information and facts provided by the therapist, relating to the cancer treatment side-effects on sexuality (Reece et al., 2010). It is important for the patient to understand that the method of treatment can have an effect on their ability to have sexual intercourse and by being involved with the decision making process will give them the ability to be prepared for their sexual changes and challenges.

Active Stage: During the active stage of treatment, assuming that the patient's sexual needs may change to be more centred on intimacy than sexual intercourse, the therapist will alter his approach accordingly, for instance approaching the patient by saying the following: "I know you told me that in addition to the fatigue, you've been bothered by a loss of interest in sex. Are you interested in having some kind of physical intimacy even while you're undergoing treatment and have you and your spouse discussed ways that you can accomplish this?"

Survivorship Stage: During the post-treatment survivorship phase, the therapist will engage in questions like "Have you been able to enjoy your intimate relationship after you surgery?" and "Are there ways you and your partner could find to enjoy intimacy with one another other than intercourse?" "Are you comfortable with different sexual techniques?" Responses that indicate a willingness to consider from different viewpoints such as: "It was hard at first, but we have found other ways to be intimate now even with the ostomy" can indicate the presence of flexible coping (Reece et al., 2010).

According to Reece and colleagues (2010) behavioural exercises should proceed in stages so that small changes in behaviour like holding hands precede larger changes in behaviour such as trying a new and different sexual activity, in accordance with the couple's success at achieving the prior behaviour change. Any successful change in a behaviour or thought towards a more flexible coping attitude should be acknowledge and validated. For many cancer survivors, sexual problems and concerns are common, persistent and often connected with other important domains of their functioning such as their relationships, self-esteem, emotional status and overall quality of life. In practise, sexual concerns are not often acknowledged and addressed in routine cancer care, and even when they are, the traditional medical approach often limits the beneficial nature of these interactions for the patient. Although Reece and colleagues (2010) proposed this alternative and broader model of coping flexibly when dealing with basic sexual concerns in breast cancer, they emphasise that future research will be necessary to develop methods of assessing flexible coping and finding the most efficient ways to implement this concept clinically into routine cancer care. A counselling approach, such as the flexibility model, which is backed up by techniques such as

cognitive strategies and behavioural exercises, is a worthy intervention modality when treating sexual dysfunctions with breast cancer patients.

#### **5.4.4 Couples therapy**

In addition to medical- and individual factors, there are also relationship influences and dynamics that play a role in how breast cancer can affect a woman's sexual functioning and body image. When one partner has a serious illness, both partners in an intimate relationship experience distress which can adversely affect their sexual relationship (Derzko et al., 2007; Dye, 2008). Manne and Badr (2008) highlighted the importance of viewing cancer from a relationship perspective and although the diagnosis of cancer in a member of the family can have substantial repercussions for the family, partners in particular are critically affected by cancer. There is considerable proof that relationships experience substantial stress during breast cancer (Nicolas, 2013; Sheppard & Ely, 2008; Walsh et al., 2005). Partners of cancer patients have to cope with certain challenges such as anxiety about the potential loss of their life partner and providing emotional and practical support under difficult circumstances. Partners can feel uncertain and at a loss about what to expect while their significant others undergo treatment and could require relevant information and support from a psychologist (Dean, 2008; Harrow, Wells, Barbour, & Cable, 2008). Apart from the emotional concerns, there are also several practical issues with which both the patient and her partner must cope with during the whole process of treatment and even after finishing the treatment. Practical stressors amongst other things can include negotiating changes in occupational and family roles, managing household and childcare chores and responsibilities and changes in future life plans. For many couples one of the main tasks during the cancer trajectory includes resuming an intimate and sexual relationship. There are also discussing changed life plans and health behaviour changes, dealing with the treatment side-effects especially chronic effects that might influence the patient's functioning, handling anxiety about disease recurrence and discussing the meaning of the cancer experience for themselves and the relationship. For couples dealing with advanced disease they have to negotiate difficult choices concerning end-of-life treatments and care such as how care and assistance with daily activities will be provided to the sick partner. They

also have to cope with anticipatory grief regarding the loss of one's partner, managing children and family's reactions and after death bequests. For couples who are in the survivorship stage of cancer, their primary challenge is to negotiate the transition from being a cancer patient to a "normal" life. One mutual challenge that couples often encounter is that each partner might have a different pace with their adaptation and acceptance of the cancer experience (Nicolas, 2013; Manne & Badr, 2008). Manne and Badr (2008) said that regardless of the stage along the cancer continuum, cancer can create unique challenges for the marital relationship, so from a couples' perspective, successful adjustment may not be as reliant on the circumstances of the cancer, but rather on how well the couple integrates the cancer into their lives.

The breast cancer patient's diagnosis, treatment, recovery or death all has an impact on the partner's adaptation and emotional well-being and they can also benefit from psychotherapeutic support at critical and difficult times for their coping abilities are also being challenged by their wife's' illness. To be a "passive bystander" is as traumatic and demanding as being the cancer patient self. The opposite is also true; that the patient's sense of support and emotional well-being are largely influenced by her partner's adjustment of the cancer and cancer experience, therefore it is important to view cancer also from a relationship perspective (Manne & Badr, 2008; Nicolas, 2013).

#### **5.4.4.1 The relationship intimacy model of couple psycho-social adaptation to cancer**

Manne and Badr (2008) have quantified the significance of regarding cancer from a relationship perspective which considers the marital relationship as a source that individual partners draw on in crisis situations. It also underlines the importance of focusing attention onto the relationship and engaging in communication behaviours aimed as sustaining and enhancing the relationship during stressful times. In the context of the above, it is important to have a proper framework to treat couples that are struggling with breast cancer. Manne and Badr (2008) had formulated the relationship intimacy model of couple psycho-social adaptation to cancer as a first step in building a framework to help clinicians to include this above mentioned areas in dealing with couples undergoing a cancer trauma. They



have proposed this model which is an all-embracing, exploratory model which they believe could help begin to organize the conceptualization of the marital relationship after the diagnosis of cancer since it integrates key components in relationship processes and outcomes.

The model focuses specifically on relationship-enhancing-behaviours. Manne and Badr (2008) the authors of this model, have selected and included three relationship-enhancing processes in their model.

- The first is disclosure of concerns and feelings regarding the cancer experience and is called reciprocal self-disclosure.
- The second process is partner responsiveness which is defined as feeling understood, cared for and accepted by one's partner. Nicolas (2013) describe these two processes together, stating that the most important process between the couple in an extreme situation like cancer is the process where the individuals expresses self-important feelings and information to one another. As a result of the other's response, the person feels that he/she is understood, validated and cared for. Openly revealing one's feelings and concerns to one another about the experience of cancer (reciprocal self-disclosure), feeling understood, validated and cared for in the relationship as a result of a partner's behaviour (partner responsiveness) and continuing to engage in behaviours to improve the relationship while also coping with cancer, are all examples of relationship enhancing behaviours.
- The third process is relationship engagement, which is an overarching term that is defined as viewing cancer in relational terms (e.g. viewing cancer as having implications for the relationship as well as for each partner individually) and participating in behaviours that are aimed at either sustaining or improving the relationship while coping with cancer. Relationship engagement is characterized by an understanding of the challenges cancer can create in the couples' relationship and an openness to talk about these changes to one another. It is also characterized by a willingness to address parts of the relationship that have either changed or need to change after the cancer, e.g. priorities and roles and lastly efforts to

maintain elements of the relationship that are important to either partner during the illness (e.g. treated each other as a spouse instead of adopting the caregiver-patient roles). Relationship-engagement emphasises relationship awareness and maintenance which are both relevant in the cancer context and can be achieved by focusing on intimacy as a primary mechanism for promoting couples adaptation.

Relationship intimacy is the main element in this model of couples' adaptation. In defining intimacy the creators of this model adopt a situation-specific approach whereby intimacy is the experience of feeling close to and being cared for by a partner with regards to the cancer experience.

The two most noteworthy characteristics of the relationship intimacy model of couple psycho-social adaptation to cancer are the fact that the model emphasises the importance of partners relating to each other as spouses rather than as a patient or caregiver and the importance of partner's efforts to maintain a level of stability in their relationship in spite of the trauma of cancer. Manne & Badr (2008) feel that partners can draw on the intimate connection between them as a source of strength and support while building a closer emotional bond which can open the door for relationship growth and simultaneously promote psychological adaptation and healing.

Sheppard and Ely (2008) have confirmed the theoretic and clinical statements of the Manne and Badr model that a breast cancer diagnosis can bring up pre-existing marital problems to the fore-ground or it can enhance a greater sense of closeness in the relationship. For example, if the couple were already far apart from each other, they may even move further apart during the process of cancer where a lot of conflict and resentment can develop, especially if the cancer patient feels that her partner doesn't understand her illness and accompanied needs. A couple that is already close to each other, will most probably move even closer to each other during the cancer journey, with very good mutual interaction and support for each other.

- **Teaching sexual communication within the framework of couples therapy**

Couples coping with cancer often experience impaired communication about their sexual problems and changes that may have emerged during this time. This lack of communication may aggravate psychological distress and decrease marital satisfaction (Hordern & Currow, 2003; Milbury, & Badr, 2013; Murray, 2010). During illness and stress most couples find it hard to talk about sexual problems and it is common for a person with a life-limiting illness to be less intimate or trusting during the crisis phase of the illness (Hordern & Currow, 2003; Murray, 2010). Often women with breast cancer develop feelings of fear of abandonment because they feel undesirable to their partners due to treatment-related changes in appearance. It often happens that the partner of the breast cancer patient will sexually withdraw for fear of causing pain or discomfort without discussing it with his partner and the partner reads it as not finding her sexually attractive anymore and might also withdraw her sexually to prevent rejection (Milbury & Badr, 2013). Another example is that the cancer patient may feel guilty for her inability to engage in sexual activities as before the cancer, where the partner feels anxious or responsible for his partner's problems. The aim here is for the therapist to help the couple remove blame and guilt and accept the perceived loss of control and to gain a realistic perspective of the illness and its effects on their sexual functioning. Adaptability is a key element in the therapy but the couple can only adapt if they are able to communicate openly about these issues. Patients must be encouraged to explore changes in their sexuality and intimacy and communicate it with their partners (Hordern & Currow, 2003). Learning to identify feelings and recognize their impact on their sexual relationship allows partners to start an improved level of communication with one another. An example is: if the breast cancer patient is able to tell her partner what feels good and how and where to touch her will improve their sexual communication (Fobair & Spiegel, 2009; Hughes, 2008; Hughes et al., 2011). Communicating feelings about their altered sexual situation may be very difficult at first for a couple given the changes and challenges both face, but is a good starting point for the communication process (Hordern & Currow, 2003). It is important to help couples to redefine their meaning of an intimate relationship and encourage them to be creative about the ways that they can exhibit sexuality and to communicate these changes in open and constructive communication to each other (Hughes et al., 2011). Teaching a couple effective open and constructive exchange of thoughts, concerns and feelings with the goal

of mutual problem-solving are effective psychological interventions and will advance both emotional intimacy and sexual satisfaction (Hordern & Currow, 2003; Milbury and Badr, 2013).

#### **5.4.5 Sexual body image and sexual functioning**

Body image is an important predictor of outcome, with measures of body image after breast cancer treatment describing up to 59% of the adjustment in the psychosocial process. It was found that more positive body image perception relates with higher self-efficacy in coping with breast cancer and its treatment, whereas heightened concern with body integrity predicts higher distress, social disruption, and deterioration in feelings of sexual desirability (Hormes, Lytle, Gross, Ahmed, Troxel, & Schmitz, 2008). A significant correlation have been found between body image and age especially for young premenopausal women who have been noted to report emotional suffering, a reduced quality of life, a loss of femininity due to fertility issues, and various sexual problems related to early induced menopause (Dalton et al., 2009; Jun et al., 2011; Nozawa et al., 2013; Rosenberg et al., 2011; Wong-Kim et al., 2005).

Breast cancer patients are exposed to changes in their physical appearance such as the loss or disfigurement of one or both breasts, lymphedema, scars from surgery and skin changes related to radiotherapy, where systemic treatments (chemotherapy or hormones) often lead to alopecia and weight increase (Dean, 2008; Krychman & Katz, 2012; Kuo et al., 2008; Reece et al., 2010). These changes are all related closely to physical appearance and body image and it is important to address these issues during psychotherapy (Derzko et al., 2007; Dye, 2008; Hughes, 2008). For the therapist it is important to remember that a mastectomy is an amputation which can disrupt body image and annihilate sexual relationships for a significant period of time (Przezdziecki et al., 2012). Some woman find it exceedingly difficult to come to terms with the breast scar especially if they perceive their partner to be repelled and bothered by the changes in her body. This is often more a case of irrational cognitive thoughts as a reality (Sheppard & Ely, 2008). An important fact to consider is that a woman's sexuality not only includes the ability to engage in sexual activity, but also her feelings and ideas about her body image and femininity and whereas sexuality is so closely

related to body image, any disruption concerning body image can lead to disturbances in sexual functioning (Dalton et al., 2009; Derzko et al., 2007; Przewdziecki et al., 2012; Sbitti et al., 2011).

Wilmoth (2001) has classified two elements that were related to post-operative body image. The first element includes the changed appearance of the patient that resulted from surgery through either the removal of the entire breast or alteration in the appearance of the breast that can influence both the nude and clothed body. In order to accept and adapt to this change, women had to experience the loss of their missing body parts and go through a grieving process. The loss or alteration of the breast(s) is the initial and most visible adjustment that confronted women as they began to accept the fact that they have breast cancer. The second element is more psychological and involves the women's perception that their womanhood and sexuality is threatened by the cancer experience. Anagnostopoulos and Myrghianni (2009) stated that breast cancer and its treatment can change a woman's definition of herself, making her feel less of a woman. These authors differentiate between a mastectomy and reconstructive surgery in term of body image in a study that they have done. Patients who had a mastectomy felt more self-conscious and less attractive, they did not like their overall appearance, were displeased with their scar and tend to avoid contact with people. Their findings were consistent with a study done by Baxter and colleagues (2006), who confirmed that women who had mastectomies had higher levels of body stigma (a need to keep her body hidden) and transparency (concerns about the obviousness of cancer-related changes to her appearance).

Since breast conserving surgery does not really alter the appearance of the breast, or cause only a small reduction or dimpling in the shape of the breast which are not noticeable to others, the visible disfigurement that can lead to a negative self-image is usually minimal. It is important to discuss both the psychological and the biological sides of the breast surgery with the patient for there can be physical discomfort and pain due to the surgery interfering with sexual activity. The therapist can provide the patient with practical alternatives such as: lying on the unaffected side to minimize the pressure on the chest areas if the incision or muscles are tender. This position will provide the patient with

more control over her movements and reducing irritation to the incision. If the patient feels any pain or discomfort over the breast area, she can ask her partner to stop, hence the importance of sexual communication. This “break” can give the patient an opportunity to rest or change position, which will also help her to relax and reduce pain (Dean, 2008; Hughes, 2008; Derzko et al., 2007).

It was established through studies that patients who feel better about their bodies also have stronger beliefs in their own ability to reach out to others for support, maintain a more positive attitude toward the cancer and remain active, self-efficient and independent (Anagnostopoulos & Myrghianni, 2009; Baxter, Goodwin, Mcleod, Dion, Devins, & Bombardier, 2006; Sheppard & Ely, 2008; Wilmoth, 2001). An important aim in therapy concerning sexual functioning and self-image is to teach the patient self-compassion, which is the ability to accept oneself and show self-directed kindness while in a stressful situation. Self-compassion comprises three components: self-kindness (vs. self-judgement), conscious awareness of emotions and understanding the universality of human suffering (vs. isolation of self) (Przedziecki et al., 2013). Teaching a patient to be kind and non-judgmental towards her own body and accepting physical imperfections, limitations and setbacks can enhance her sexual body image. This can be done in the framework of CBT where negative and deconstructive thoughts about self-image can be identified and be consciously changed to positive and friendlier thoughts. A study done on the effect of CBT of breast cancer patient’s body-image dissatisfaction found that patients made significant gains on the multiple measures of the presenting target complaints (Almas & Landmark, 2010). Treatment can enhance a patient’s social self-esteem, improved her sexual interest and feelings, and promoted more positive evaluation of physical fitness (Almås, & Landmark, 2010). It is also important to emphasize practical matters, for instance to go on a regular basis (if possible) for body and facial massages to “spoil” the body and keep it in good order and to concentrate on the rest of the body that is not affected by the cancer (Przedziecki et al., 2012). Breast cancer patients often want to talk about their (altered) appearance and what to do about it and how to accommodate it. It is important for the breast cancer patients to hear that therapeutic interventions are not always just about the (more difficult) psychological processes, but can also be more practical as in to change the way they dress,

especially if they have lymphedema or have a breast prosthesis or have gained a considerable amount of weight. Przedziecki and colleagues (2012) feel strongly that self-compassion enhancement is one of the most active ingredients in effective body image intervention. Therapeutically it is vital for the breast cancer patient to come to terms with her “new” sexual self or sexual identity during and after the treatment of cancer and to use it for her advantage in sustaining healthy and active sexual functioning.

#### **5.4.6 Specific breast cancer symptoms and treatment related sexual functioning**

The most important and relevant sexual components and functions in the context of cancer treatment and psychotherapy have been covered in this chapter, but because of the frequency and impact of certain specific cancer related symptoms and the importance of implementing effective interventions, I will briefly describe them in the framework of therapeutic interventions.

##### **5.4.6.1 Psycho-social menopausal symptoms and Treatment**

Menopausal symptoms are a frequent complaint of breast cancer patients during and after the cancer treatment with the main psycho-social menopausal symptom that of low self-esteem resulting from a psycho-sexual dysfunction which is often caused by a decreased libido and consequent relationship problems (Dean, 2008; Hughes, 2008). As a therapist it is important to remember that menopausal symptoms resulting from cancer treatments are not always discussed with the patient before treatment, so they often experience these symptoms alone and in silence and therefore it is important to always ask about, and incorporate it in therapy (Dalton et al., 2009; Hughes, 2008). Menopause can have a huge impact on a woman's sexuality because of changes in her body including vaginal dryness, loss of vaginal tissue elasticity, hot flashes, insomnia, irritability and mood swings, each of which can affect sexual interest and sexual functioning (Dean, 2008; Hughes, 2008). It is important to talk about the effectiveness of taking medication for menopausal symptoms, what kind of medication to use, what type of symptoms it can relieve and who can prescribe it. Pharmacological options that are most effective are anti-depressants (that are discussed in 4.4.2.7) specifically Venlafaxine 75 mg and Paroxetine that were found to reduce hot flashes and can

also attend to the patients' mood. The anticonvulsant drug Neurontin can also be prescribed. It has been found that Wellbutrin SR 300mg daily can increase sexual arousal and orgasm intensity and overall sexual satisfaction (Fobair & Spiegel, 2009; Krychman & Katz, 2012; Kuo et al., 2008).

#### **5.4.6.2 Fatigue**

Many cancer patients experience fatigue and lethargy as a direct side-effect of cancer treatment, which affects the way they feel as a person and how they relate to others (Berger et al., 2015). It is important to ask how fatigue is affecting the patient and her relationship, emphasising the importance of non-penetrative sex and encouraging them to explore what makes them feel good about themselves and the type of things they once enjoyed sharing with their partner (Dean, 2008; Hordern & Currow, 2003). Patients will find it helpful to learn to plan their activities, preserving energy on tasks that are less important, to learn to prioritise their activities and to know when to rest without feeling guilty. They can then figure out what time during the day do they tend to feel least fatigued and plan their sexual activity for the time of the day when symptoms tend to be least bothersome (Nusbaum et al., 2003). In the context of sexual activity, this might feel a bit forced, depriving the patient of some of the spontaneity they would have liked, but allow them more scope for a better functioning sexual relationship with her partner if fatigue is making her sexual life difficult (Dean, 2008).

By using their best time of the day (when they have more energy, less pain, or fewer problems with other symptoms) and by setting realistic and achievable goals, they will feel more in touch with themselves and their partners (Dean, 2008; Hordern & Currow, 2003). It is important for the patient to “save” her energy for important activities and to learn to listen to her own body, to know when to rest and what activities take the most out of their energy “reservoir” and replace it with less active activities.

#### **5.4.6.3 Pain**

Vaginal dryness as a result of chemotherapy and hormonal treatment can cause pain and discomfort and in extreme cases vaginismus (Hughes, 2008; Hordern & Currow, 2003; Weinera & Avery-Clark, 2014). A woman who experiences pain (a



physical response) during intercourse may fear (a psychological response) that future sexual encounters will result in pain which can cause avoidance of intimate behaviour. Vaginal dryness during sexual activity can be treated symptomatically with commercial lubricants and it is important to explain or reinforce the use of vaginal lubricants and moisturizers to your patient who need to understand how they work. There are two different types of lubrication, the one is a lubricant (glycerine-free water based) which the patient use before and during sexual activity, whereas vaginal moisturizers are used several times a week to help maintain normal vaginal moisture and comfort. The patient and her partner should be encouraged to try out new products (Derzko et al., 2007; Krychman & Katz, 2012; Reece et al., 2010). Giving and explaining the more practical elements of sexual functioning goes down very well with cancer patients and although it might sound very basic (the using of lubrications for instance) a lot of women, especially younger women who are in a new and unexpected menopausal status, have never had to use lubrications before and do not always have the confidence to talk it through with their oncology team (Derzko et al., 2007; Hughes, 2008).

The purpose of CBT with sex related pain is to achieve pain control by the patient self which will focus on reducing catastrophic fear of pain through conscious mind control, re-establishing overall satisfying sexual functioning through different and flexible thoughts and sexual activities and non-penetrative sex and the enhancement of intimacy. The therapist will also educate the patient on dyspareunia, especially how it can affect desire and arousal and the overall sexual functioning, progressive muscle relaxation and abdominal breathing, vaginal dilation, cognitive distraction techniques focusing on sexual imagery and cognitive restructuring (flexible thoughts) and communication skills training (Hughes, 2008; Weinera & Avery-Clark, 2014). Sexuality and intimacy can be a time of gentle relaxation for patients, when sharing and touching can improve their sense of well-being. If patients have biological pain, the health professional should specifically ensure that they take breakthrough analgesia before times of intimacy or physical sexuality (Hordern, & Currow, 2003).

In the case of vaginismus, the use of gradual exposure and applied relaxation (systematic desensitization) are one of the core elements in treating. Gradual

exposure exercises (sensate exercises) can be assigned for homework including gradual process to vaginal touching, usually by beginning with the woman's fingers and dilators up to penetration. These elements are often part of a broader approach involving cognitive restructuring, education and broader, more inclusive sex therapy (Masters & Johnson, 1970; Meier, 2010).

#### **5.4.6.4 Decreased libido and orgasmic problems**

Women should be advised during the therapeutic process that an age-related and menopausal lowered spontaneous (biological driven urge) sex drive is not abnormal. It is important that breast cancer patients, including those on AI therapy and younger patients be made aware of this. Even if the biological sexual urge is not always present, they can be motivated to be sexual for other reasons, for instance to generate emotional closeness, reassurance of a loving relationship and partner satisfaction. It is also important to medically address any potentially reversible causes such as dyspareunia, depression, hormonal alterations and medications that can have an impact on libido. If this is out of the range of the psychologist, then the patient must be referred back to the medical specialist (Derzko et al., 2007). A decrease in lack of libido can be improved by watching erotica for instance. It is important to know your patient's stance (conservative vs. liberal) about using alternatives like watching erotic movies or looking at erotic journalism with her partner to better her libido, but is also important that the patient must do what they feel comfortable with (Hughes, 2008). They can be encouraged to talk about their sexual fantasies with their partners and regular sexual encounters may need to be scheduled to "drive" them to participate in sex and intimacy to keep their relationship on a healthy level (Hughes, 2008).

Another alternative to help your breast cancer patient to enhance a low libido is to focus on self-stimulating. Sensate focus exercises are also helpful in treating a low libido. Another technique to enhance arousal and orgasm is increased intensity and duration of genital, especially clitoral, stimulation (Derzko et al., 2007).

## 5.6 PRACTICAL IMPLICATIONS AND SUMMARY

To summarize sexual functioning and interventions in the cancer framework I have used the American Cancer Society's (2013) practical guidelines for cancer patients for their sexual wellness during cancer and cancer treatment.

### **The American Cancer Society's Practical Guidelines for Sexual Wellness (2013) are:**

1. As a cancer patient - learn as much as possible about the effects of cancer and cancer treatment on your sexuality and talk to your oncologist or oncology team about sexual matters.
2. Understand that in spite of any kind of cancer treatment you as the patient will still be able to feel pleasure from touching, even if it means non-genital touching and stroking.
3. Try to have an open mind about ways to feel sexual pleasure and if necessary to broaden your view of sex and sexual intercourse and learn new ways to give and receive sexual pleasure.
4. Implement a clear two-way communication about sex with your partner and with your doctor (or psychologist) too. Good communication is the key to adjusting sexual routine when cancer changes your body and it is important to communicate pain or tenderness in some parts of your body and to guide your partner's touches to create the pleasure and to avoid pain.
5. Learn to improve your self-esteem (including sexual self-esteem) and focus on your good qualities. If your hair falls out, decide what to wear, e.g. a wig or a hat or a scarf, whatever makes you feel good and beautiful. Eating right and exercising (after consulting with the Doctor) can also help keep the body strong and the spirits up.
6. Practice relaxation- and breathing techniques, and
7. Request professional help when depressed or anxious.

Health professionals must incorporate patient sexuality and intimacy into routine palliative assessments, so that every patient is given an opportunity to explore these issues. Patients and their partners will appreciate health professionals providing information, support and practical strategies related to issues of intimacy

and sexuality throughout the course of care. In the light of this, there is a growing recognition that there are still limitations in the way that sexual concerns are currently being addressed in cancer patients. According to Reese and colleagues (2010) there are few intervention studies addressing adjustment following cancer that target sexuality and even fewer that are entirely focused on addressing sexuality especially in woman. Krychman and Katz (2012) believed that this field is ripe for studies of psycho-social interventions as an adjunct to or in place of pharmacologic treatments in this population and that further research is warranted.

## CHAPTER VI

### RESEARCH METHOD: CASE STUDY DESIGN

Case study research, which was the design of this study, is a valuable method for health science research. It lends itself to exploring real life experiences and situations where the researcher is interested in the occurrence and the context in which it occurs. In this particular case, the breast cancer experience through the lived experience of the breast cancer patient self. Case studies are typically descriptive in nature and provide rich, in-depth and longitudinal information. It aims to investigate a particular topic in its natural context from multiple angles (Baxter & Jack, 2008; Lindegger, 2006; Salminen et al., 2006; Simons, 2009; Terre Blance et al., 2006). Because of the sensitivity of the subject of breast cancer and the in-depth understanding needed, the justification of this study will be better comprehended against the background of a qualitative research paradigm.

As the researcher, I have used a combination of qualitative research methods and quantitative methods, combining these two methods by applying two standardised questionnaires together with the qualitative information methods to gather data regarding depression and anxiety and sexual functioning in the breast cancer population. These combined methods can be applied where the study requires measurement of some kind (quantitative method), but also deeper understanding of the nature of an issue (qualitative method) (Ormston et al., 2014).

#### 6.1 AIMS OF THE STUDY

The researcher's aim with this study was to develop a clearer understanding of the lived experiences and perceptions of the breast cancer patient through exploring and analysing her experience of her illness and unique needs for further psychological interventions through her own personal interpretation and voice. The researcher hopes that this study will make a valuable contribution to research in the oncology field in South Africa and initiate new ways of understanding the role of psychology and the psychologist in the medical world of cancer. The study further aim to use this deep and unique knowledge from the breast cancer patients and survivors to fill the gap between clinical knowledge and practice by

implementing individual psychotherapy and sex therapy as part of a holistic psycho-oncology treatment plan.

## **6.2 PHILOSOPHICAL, PARADIGM AND INTERPRETIVE FRAMEWORKS AND DEFINITIONS**

### **6.2.1 Paradigm**

A paradigm or worldview is defined as a basic set of assumptions and beliefs that are shared by members of the scientific community that guide researchers in their inquiry (Bezuidenhoud, 2014; Creswell, 2007). A paradigm consists of the following components: a) ontology, b) epistemology, c) methodology and d) methods (Scotland, 2012). The aim of a research paradigm is to anchor a study and serves as a map directing the researcher in all the stages of the research process (Bezuidenhoud, 2014; Guba & Lincoln, 1994; Schurink & Schurink).

#### **6.2.1.1 Ontology**

Ontology is the study of 'being' and is concerned with what reality represents (Scotland, 2012). Reality can be described as something that is subjective and multiple and when studying individuals, qualitative researchers conduct a study with the intent of reporting these multiple realities. According to Scotland (2012) there is a distinction between a scientific paradigm and an interpretivist paradigm each with its own ontology. The ontology of the scientific paradigm (positivists) is realism which is based on the notion that there is an external reality which exists independently of a person's belief about or understanding of it. They argue that there is but one true reality that is apprehendable, identifiable and measurable and use mainly quantitative methodology. The ontological position of interpretivism (post-positivists) is relativism or idealism which proclaims that reality is subjective, differs from person to person and is mediated by a person's senses and is only knowable through the human mind and through socially constructed meanings (Guba & Lincoln, 1994; Ormston et al., 2014; Scotland, 2012). Reality, according to the constructivist position, is influenced by the context of the situation, namely the individual's experience and perceptions, the social environment and the interaction between the individual (study participant) and the researcher (Creswell, 2007, 2015; Ormston et al., 2014; Ponterotto, 2005).

The guiding ontological framework for this study is that of constructivists-interpretivists against the background of relativism, providing the framework for studying the breast cancer patient's experience and perceptions of her illness, her social environment regarding her interactions with the oncology team and her family and her social support system and the interaction process between her and the researcher.

#### **6.2.1.2 Epistemology**

Epistemology has to do with the relationship between the research participant and the researcher where the researcher attempts to lessen the distance between him/her and the participant through cooperating, spending time in the field with the participants and becomes an "insider" in their lives (Creswell, 2007; Ponterotto, 2005). Crotty (1998) offers three primary epistemological influences namely: objectivism, constructionism and subjectivism. There are several paradigms used to guide research and different authors incorporate different paradigmatic schemas to conceptualize and classify their research (Creswell, 2007; Denzin & Lincoln, 2000; Guba, & Lincoln, 1994; Ponterotto, 2005; Schurink & Schurink, 2012). The Constructivist (or interpretivist) paradigm is the chosen epistemological paradigm that will guide this study and where the researcher will briefly describe this approach through the lens of Guba & Lincoln (1994), which is the most suitable classification for this study.

#### **The Constructivist–Interpretivist Paradigm:**

This paradigm can be seen as an alternative to the positivist paradigm of dualism and objectivism and in marked contrast to positivist's single, inflexible objective external reality. Constructivism adheres to a relativist position that adopts multiple, apprehendable and equally valid realities, which supports the beliefs of this study. Constructivists believe that reality is constructed in the mind of the individual rather than it being an externally extraordinary object (Ponterotto, 2005). Both Stake (1994) and Yin (2003) have based their approach to case study on a constructivist paradigm. Constructivists, according to these authors, claim that truth is relative and that it is dependent on one's perspective. Creswell (2007) understands that individuals seek understanding of the world in which they live and work through personal or subjective meanings of their experiences. As the

researcher, I am interested in the understanding of the world of the breast cancer patient during active treatment and when in remission. A distinguishing characteristic of constructivism is the centrality of the interaction between the investigator and the object of investigation (participant) and only through this interaction can deeper meaning be uncovered. The goal of this paradigm which also shares the goal of this study is to rely as much as possible on the participants' lived experiences with their illness and to be able to evaluate and assess these personal experiences through experiencing it first-hand with them in their environment, in this case through a lengthy therapeutic process (Ponterotto, 2005; Schwandt, 2000).

- **Constructivist paradigm:** Rather than starting with a theory, researchers within the constructivist paradigm generate a theory of meaning and value. In practice, the questions are broad and general and open-ended, so that the participant can create his/her own meaning of a situation. The constructivist researcher listens carefully to what people say or do and addresses the processes of interaction among individuals (Creswell, 2007). Constructivism is built on the principle of a social structure of reality, with one of the advantages of this approach, the close relationship between the researcher and the participant, while facilitating and empowering the participant to tell her story (Baxter & Jack, 2008; Guba & Lincoln, 1994)
- **Interpretivist paradigm:** is a methodological approach more typical to qualitative research, advocating an interpretative understanding and explanation that enables the researcher to appreciate the subjective meaning of social action (Symon & Cassell, 2012). Schurink and Schurink (2012) believe that reality should be interpreted through the meaning that research participants give to their life world. This approach provides a deep insight into the complex world of lived experiences from the view point of the individuals who live it and believe in multiple perspectives rather than a single reality (Andrade, 2009; Creswell, 2013). The researcher's intention with this study was to attempt to understand the breast cancer patient better through the subjective interpretation of those who experience it.
- **Phenomenological methodology:** Because the researcher's intention is to understand the breast cancer patient better through subjective



interpretation and consciousness within the context of her own unique experience, the researcher has also borrowed some principles of the phenomenological methodology known to use thick description and close analysis of lived experience to understand how meaning is created through personified awareness (Groenewald, 2004; Lavery, 2003).

### **6.2.1.3 Axiology**

Axiology involves the role of researcher values in the scientific process (Creswell, 2007). Positivists argue that there is no place for values in the research process and the psychology researcher should remain emotionally detached from the investigative inquiry. By using standardized, systematic investigative methods (quantitative research), the researcher eliminates and controls any influence he or she might have on the participant's or on the research process (Guba, & Lincoln, 1994; Ponterotto, 2005). Constructivists-interpretivists support the fact that the researcher's values and lived experience cannot be separated or removed from the research process and the researcher should then acknowledge, describe and categorise his/her values, but not eliminate them (Guba & Lincoln, 1994). It is important to keep in mind that the epistemology underlying a constructivist position necessitates close and prolonged interpersonal contact with the participant in order to facilitate their construction and expression of their lived experience that is being studied (Ponterotto, 2005). In conducting this study, the researcher, who also participates as a clinical psychologist in a therapeutic role with the study participants, has developed a close and lengthy patient–therapist relationship and interaction with the participants resulting in being able to have observed and gained in-depth material directly from them.

### **6.2.1.4 Rhetoric**

This terminology refers to the language used to present the procedures and results to the intended audience or reader (Creswell, 2007; Ponterotto, 2005). Rhetoric or language arises closely from the researcher's epistemological and axiological viewpoint. In the Positivist positions where objectivity and emotionally neutral research role succeeds, the language is precise and scientific and will be presented in an objective manner, where in the constructivist-interpretivism position, a subjective and interactive researcher role predominates. The language

of the research report will be more likely in the first person and is often personalized (Creswell, 2007; Ponterotto, 2005). Qualitative researchers make use of a more literary informal style of writing using the personal voice of the participant and use qualitative terminology such as credibility, transferability, dependability and confirmability or validation instead of quantitative language such as internal- and external validity, generalisability and objectivity. The qualitative vocabulary will use words such as “understanding”, “discover” and “meaning” and are important language indicators in writing purposes statements and research questions (Creswell, 2007).

#### **6.2.1.5 Methodology**

Methodology refers to the strategy or plan of action which lies behind the choice and use of specific methods (Creswell, 2007; Crotty, 1998; Ponterotto, 2005; Scotland, 2014). Methodology is concerned with why, what, when, from where and how data is collected and analysed (Scotland, 2014). Against the background of this study’s interpretivism paradigm, the interpretive methodology is directed at understanding a phenomenon or experience from an individual’s perspective, exploring interaction amongst individuals and also the historical and cultural contexts which people populate (Creswell, 2009; Scotland, 2012). The four examples of methodology include: a) case studies, which are the in-depth studying of cases or events over a lengthy period of time; b) phenomenology, the study of close experience without allowing for obstruction of current prejudices; c) hermeneutics, which draws hidden meaning from language; and d) ethnography, the study of cultural groups over a prolonged period of time (Scotland, 2012).

#### **6.2.1.6 Methods**

Methods are the specific techniques and procedures used to collect the data and to analyse it and will either be qualitative or quantitative (Crotty, 1998; Scotland, 2014). Research method emerges naturally from the researcher’s position on ontology, epistemology and axiology (Ponterotto, 2005). Where Positivists attempt to replicate strict scientific methods and procedures where variables are carefully controlled and the researcher’s emotional perspective on the research subject is irrelevant, the constructivists/interpretivist on the other hand, give their outlook on the significance of intense researcher-participant interaction and on the need to be

absorbed in the participants' world over longer periods of time. As the researcher of this study, I have embraced the naturalistic designs where the researcher is established in the specific study population and their day-to-day lives, which could lead to qualitative research methods such as in-depth face-to-face interviewing and participant observation, which was applicable in this study (Lincoln & Guba, 1985; Ponterotto, 2005).

### **6.3 QUALITATIVE RESEARCH**

Qualitative research methods are unique and valuable for studying the complexities of the healthcare system and in particular patient experiences (Smith & Firth, 2011). Because this study explicitly relies on understanding the breast cancer patient's unique experiences and specific needs regarding their cancer and relationships with the cancer professionals, the qualitative approach will be appropriate for exploring and describing the complexities of health issues and can facilitate, through this type of data gathering and analysis methods, a deep understanding of the patient's experience (Smith & Firth, 2011)

#### **6.3.1 The characteristics of qualitative research that has guided this study**

Qualitative methods refer to a broad class of empirical procedures designed to study things in their natural surroundings, attempting to make sense of, or interpret events in terms of the meanings people bring to them (Creswell, 2007; Denzin & Lincoln, 2005). In short, according to Creswell (2007) qualitative methods make the world visible. Ormston and colleagues (2014) described qualitative research as a naturalistic, interpretative approach, involving exploring phenomena from the inside and taking the perspectives and explanations of research participants as a starting point. Theories and models don't explain the reasons why people respond the way they do, or the specific context in which they responded or their deeper and meaningful thoughts and behaviours that directed this responses, although they provide a general picture of tendencies, associations and relationships (Denzin & Lincoln, 2000).

Qualitative research begins with an assumption, a paradigm, the possible use of a theoretical lens, and the study of research problems or phenomena, inquiring into the meaning individuals assign to a human problem. To study this problem or

phenomenon, qualitative researchers use a developing qualitative approach to inquiry, the collection of data in a natural setting sensitive to the people under study and data analysis that is inductive and establishes patterns of themes (Creswell, 2007). Although there are different opinions about the amount of literature needed before a study begins, qualitative texts refer to the need to review the literature so that the researcher can provide the rationale for the problem and position the study within the on-going literature. This study has conducted a thorough literature review first, prior to the data collection process, on breast cancer research done internationally and in South Africa to have acquired an understanding of the topic. The aim with the literature review was to see what has already been done on breast cancer, how it was researched and what the key issues were, as well as the criticisms and restrictions on the topic (Hart, 1998).

The final written report or presentation then includes the voices of the participants, the interpretation of the researcher and a multiplex description and interpretation of the problem. In writing up the findings of the study, the qualitative researcher will make use of everyday language and often incorporate the participants' own words to describe an experience or phenomenon (Ponterotto, 2005). By creating dialogue and heightening awareness, as described by Creswell (2007) it was hoped by the researcher that this research study can lead to a better understanding of the psychological pathology and experiences of the breast cancer patient and their need for further psychological interventions and through that insight lead to improvements in the oncology practice.

I support the belief of Denzin and Lincoln (2003) that the way people experience life is too complex and rich to be reduced to numbers and statistics as is the practise of quantitative research methods. Rather than predicting and generalising, the practising of qualitative research has placed importance and worth on the human interpretation of their lived experiences and on the meaning of both the participants' and investigators' interpretations and comprehension of the phenomenon being studied (Denzin & Lincoln, 2003; Ormston et al., 2014). Although this study used elements of both methods, the largest part of the study relied on a qualitative research approach because it offers tools for the researcher to study selected and complex issues in depth. Osborne (1994) explained that

when a researcher decides on a qualitative enquiry and must make a decision as to which qualitative methods are best for the study, an important element to take into consideration is that the chosen methods should be a function of the research question to be answered and not just a mere commitment to the theoretical philosophy.

Table 6.1 presents a summary of the practical characteristics of qualitative research that the researcher has used in this study and described by Creswell, (2007), Ritchie and Lewis (2003) and Ormston and colleagues (2014).

**Table 6.1: Description of the common characteristics of qualitative research that was used in this study:**

CHARACTERISTIC	DESCRIPTION	THIS STUDY
<b>Naturalistic</b>	<p>This means studying real-world situations in a natural, non-manipulative and non-controlling way with an openness to anything that can emerge with no predetermined limits on outcomes.</p> <p>Qualitative researchers collect data in the field and gathered information by talking directly to people and seeing them perform within their context.</p>	<p>The researcher has collected data from the study patients during individual psycho-therapeutic sessions to explore their unique lived experiences with their breast cancer diagnosis or survivorship in their own natural environment.</p>
<b>Researcher as key instrument</b>	<p>The qualitative researchers collect data themselves through examining documents, observing behaviour and interviewing participants. Data is collected during close relationships</p>	<p>As the researcher I have adapted the role of a clinical psychologist who did psychotherapy with the breast cancer patients, allowing me to observe and have personal interaction with them in a</p>

CHARACTERISTIC	DESCRIPTION	THIS STUDY
	between the researcher and the participant.	close and confidential psychotherapeutic relationship. This was done either in the practise or the hospital during and after their cancer treatment.
<b>Interaction between researcher and study participants and participants' meanings</b>	Qualitative researchers aim to understand a deep structure of knowledge that only develops from personal interaction with the participants, spending extensive time in the field and delving to gather detailed meanings.	The researcher has developed a therapist – patient relationship with the five study patients and was involved in a therapeutic process for more or less a year evaluating the breast cancer patient's unique meaning of their experience.
<b>Samples</b>	Samples are small and selected according to specific criteria.	This study included five breast cancer patients and survivors that were selected according to certain criteria.
<b>Multiple sources of data</b>	Qualitative researchers gather multiple forms of data, during close relationships between the researcher and participant, such as as interviews, observations and documents, rather than rely on a single data source.	This researcher has used the close, therapeutic relationship between her and the breast cancer patient to gather data in the form of "interviews" or therapeutic interactions and direct observations during the therapeutic process. Two structured questionnaires were used, as was a literature study.
<b>Inductive data analysis</b>	Data-analysis are flexible and clear, supporting complexity and progression and reflects	As the researcher I have started transcribing the "raw" notes after every session, I

CHARACTERISTIC	DESCRIPTION	THIS STUDY
	<p>the uniqueness of each participant. Occurrences created from in-depth, detailed descriptions of the phenomena are based on the lived experiences and perspectives of the participants.</p> <p>Qualitative researchers review all of the data; make sense of them and organizing them into categories or themes from a “bottom-up” process that cuts across all of the data sources.</p> <p>Researchers then work back and forth between the themes and the database until they establish a comprehensive set of themes.</p>	<p>have then worked through them back and forth and had systematically sorted them firstly into core categories and sub-categories and then into an inclusive set of themes.</p>
<b>Interpretive inquiry</b>	<p>Qualitative research is a form of inquiry in which researchers make an interpretation of what they see, hear and understand. The researcher’s interpretations cannot be separated from their own background, history, context and prior understandings.</p>	<p>I have observed and listened to the five participants during conversations and therapeutic sessions/interactions and with my experience of working with breast cancer patients and deep interests in breast cancer, made certain interpretations which were reported in rich and comprehensive descriptions.</p>
<b>Holistic account</b>	<p>Holism consists of reporting</p>	<p>I have taken all the different</p>

CHARACTERISTIC	DESCRIPTION	THIS STUDY
	various perspectives; identifying different factors involved in a situation and sketches in general the larger picture that develops. Qualitative researchers aim to identify complex interactions of different factors in any situation and don't rely on rigid cause-and-effect relationships between factors.	aspects and stages of a breast cancer diagnosis into consideration, putting it into both a medical- and psycho-oncologic framework and reported a holistic picture of the breast cancer patient and survivor in terms of her own personal and unique experiences and needs.

The practising of qualitative research (Ormston et al., 2014), has placed emphasis and worth on human interpretation of the social world and the importance of both participants' and the investigators' interpretations and understanding of the phenomenon being studied. Besides this discussion and understanding of the phenomenon, a qualitative study may also fill a void in existing literature, create a new line of thinking or evaluate an issue with an understudied group.

### 6.3.2 Literature review as part of a qualitative method

The primary use of a literature review is to provide the rationale for the problem and to help the researcher to become familiar with the challenges, limits and language of the type of research they aim to conduct and to provide the contextualisation for the arguments of the study (Creswell, 2007; Henning et al., 2004; Ormston et al., 2014). When a preliminary idea for a study has been theorized the researcher will then need to examine how other researchers have thought about and researched the topic and need to gain perspective on the phenomenon or problem and be able to connect the past with the present (Denyer & Tranfield, 2006; Jaccard & Jacoby, 2010).

Through examining the literature, it was clear that breast cancer survivors are officially the leading group of cancer survivors amongst women in the Western world, indicating the critical need to find creative strategies to assist this population in coming to terms with, and live with their cancer reality (Fischer, Dolbeault, Sultan



& Bredart, 2014; Greeff, 2008; Hummel et al., 2015). Psycho-oncology is a relatively new field that has started to develop as a sub-specialty in oncology and psychology and Holland (2002) claims that over the next years new research will give a scientific basis for interventions and a reduction in the barriers to psychosocial care in cancer. Venter (2014) who found that the majority of studies done in South Africa focussed on the bio-medical aspects of cancer where only 16% of studies during this timeframe was focused on psychosocial factors. Venter feels that despite the need for a bio-psycho-social approach, there seems to be limited literature available on the psychological adjustment of cancer patients in South Africa.

### **6.3.3 Case study research**

There are five qualitative approaches to inquiry, namely: Narrative research, Phenomenology research, Grounded theory, Ethnography and Case study research. The chosen approach for this study was case study research.

#### **6.3.3.1 Definition and background**

Case study research is used to explore real life experiences and situations where the researcher is interested in the occurrence and the context in which it occurs. Case studies are typically descriptive in nature and provide rich, in-depth and longitudinal information and aims to investigate a particular topic in its context from multiple angles (Lindegger, 2006; Salminen et al., 2006; Simons, 2009). An advantage of case studies is that it allows new ideas and hypotheses that emerge from careful and detailed observation. What makes the case study research applicable in this study is that it can be a useful approach when studying professional practice and problems of practical significances in the case of psycho-oncology, which can enable practitioners to re-conceptualise a practical problem and comprehend it more fully to incorporate theory and practice (Golby, 1994; Salminen et al., 2006).

Specific features associated with case studies and which provided the guidelines for this study are:

- It focuses on an individual unit.

- It assists the researcher to understand complex issues and inter-relationships.
- The study is intensive and detailed and grounded in “lived reality”.
- The phenomenon is studied in its context.
- Case studies can present the processes involved in causal relationships.
- Multiple data-collection methods were used, and data results are able to facilitate rich conceptual or theoretical development (Hodkinson & Hodkinson, 2001; Lewis, Ritchie, Ormston, & Morell, 2014).

Stake (1995) and Yin (2003) base their approach to case study on a constructivist paradigm which recognises the importance of the subjective human creation of meaning, but doesn't outright reject some notion of objectivity. This study supported constructivism/interpretivism as the chosen epistemological paradigm embracing the naturalistic and holistic themes to guide the descriptive and exploratory multiple case study design. Marshall and Rossman (2014) stated that qualitative studies often include both descriptive and exploratory methods for the mere fact that they build rich descriptions of complex circumstances that are unexplored in the literature. Case studies can be categorised as explanatory, exploratory or descriptive and differentiates amongst single-, holistic- and multiple-case studies (Creswell, 2007; Durrheim, 2006; Stake, 1994; Yin, 2003, 2014). A description of exploratory, descriptive and multiple-cases studies will follow in Table 6.2 to give the reader a clearer picture of the framework of this study:

**Table 6.2: Definitions of the categories of case studies that were used in this study**

Concept	Definition
<b>Exploratory:</b>	This type of study is conducted for preliminary investigations into relatively unknown areas of research and to explore situations in which the intervention being evaluated does not have a clear single set of outcomes (Creswell, 2007; Terre Blance 2006; Yin, 2003).
<b>Descriptive:</b>	This type of case study is to describe an intervention

Concept	Definition
	or phenomenon in the real life context in which it occurred (Durrheim, 2006; Yin, 2003, 2014).
<b>Multiple-case studies:</b>	This type of study enables the researcher to explore differences within and between cases with the goal of replicating findings across cases. Because links and comparisons will be drawn, the cases were carefully chosen for the researcher to predict similar results across cases or predict contrasting results based on a theory (Durrheim, 2008; Stake, 1995; Yin, 2003).

In spite of the strong features of case studies that benefited this study, the researcher was attentive to accommodate the limitations and to have worked around it as to not disadvantage the study because of that. Hodkinson and Hodkinson (2001) gave a short description of the six limitations of case studies:

- Case studies can generate too much data for easy analysis and even with detailed reporting it can still be a simplification of the data.
- If the sample is too big, it can be very expensive and time-consuming to collect the data.
- The findings of most case studies cannot be explained in a linear fashion, which can make it difficult to summarise the results.
- The findings of a case study do not lend themselves to numerical representation which makes it not generalizable in the conventional sense.
- Because the sample sizes are often small and unique and essentially non-numerical, there is no definite way to establish the possibility that the data is representative of some larger population therefore some researchers find case study results of little value.

### **6.3.3.2 Multiple case studies**

Single and multiple case study designs are variants within the same methodological framework with the defining feature of a multiple case study design that the researcher examines more than one case to illustrate the research

problem and to show different perspectives of the issue or problem (Creswell, 2007; Yin, 2003, 2014). Each individual case study consists of a “whole” study where the researcher replicates the procedures for each case and in which concurrent evidence is pursued. In this study the researcher wanted to examine the whole spectrum of the breast cancer experience throughout the active cancer treatment and survivorship. This was done within the framework of different ages and stages of the cancer and treatment together with their related and relevant needs. Because of these differences, the researcher has chosen multiple cases. Multiple case designs add reliability to the findings of the study and may offer deeper understanding of cases than single case designs. The evidence from multiple cases is often considered more compelling and the overall study is therefore regarded as being more robust and stronger than single case designs (Salminen, 2006; Yin, 2003). Although multiple case studies are more expensive and time-consuming to conduct, they are preferred over single-case designs because their analytic benefits are more substantial and powerful (Baxter & Jack, 2008; Yin, 2003). Multiple cases, as opposed to a single case can enhance external validity and prevent observer bias (Creswell, 2007; Durrheim, 2006).

#### **6.3.3.3 Case selection**

The most important criterion in case selection is to ensure that the selection allows for the maximum amount of information to be learned from the cases in question (Salminen et al., 2006). Purposeful sampling, which is a commonly used method of case selection in qualitative research, means the researcher selects certain individuals for the study because they have the best knowledge of the research topic and therefore can purposefully contribute to the research problem and central phenomenon (Creswell, 2007, 2013; Elo et al., 2014; Patton, 2002). The researcher, within the multiple case study design, will look for a participant to include in the study who understands the phenomenon under study, who is articulate, reflective and willing to share her feelings and experiences with the interviewer/researcher (Coyne, 1997; Elo et al., 2014). The participant will be selected according to critical analysis of the specific population being studied and with the assumption that the participant will add value to the outcome of the study (Silverman, 2001). Although sampling procedures in qualitative research are not so rigidly prescribed as in quantitative studies, Seawright and Gerring (2008),

gave a relatively narrow definition of sample procedure stating that it is the intensive analysis of a single case or a small number of cases where the researcher's goal is to understand a larger class of similar cases (a population of cases). These authors believe that the chosen individual is asked to perform a "heroic" role to represent a population of cases that is often much bigger than the case itself.

#### **6.3.3.3.1 Number of participants**

The number of cases that should be selected is an important decision in sampling strategy in the data collection process (Creswell, 2007; Voss, Tsiriktsis, & Frohlich, 2002). A smaller number of cases facilitate greater opportunity for depth of observation and because of the labour intensity of qualitative research, a large sample can be time consuming, expensive and sometimes just impractical (Coyne, 1997; Creswell, 2007; Mason, 2010; Seawright & Gerring, 2008; Terre Blance, 2006; Voss et al., 2002). There is no set number of cases, but Creswell (2007) states that he would not include more than four or five cases, for this amount should provide sufficient opportunity to collect extensive detail about each individual and to identify themes of the cases as well as conduct cross-case theme analysis. Creswell warns that if there are too many cases, the uniqueness and depth of the cases can be lost. According to Terre Blance (2006) and Richie and colleagues (2013) there are a number of issues that can help the researcher to determine the sample size, which was implemented in this study:

- The heterogeneity of the study population; if the population is relatively homogeneous, as in this study where all the participants' were breast cancer patients or survivors, a smaller sample will be representative of the study population and will include all the internal variety that is needed;
- For reasons of comparison.
- Practical constraints such as the budget and resources available, for each sample unit will need intensive resources for data collection and analysis.

Because there was only researcher in this study, a smaller number of cases were more practical, manageable and affordable.

To lessen concerns regarding small sample size, Patton (2002) stated that researchers must be careful not to over-generalise from purposeful samples, but rather maximising the advantages of in-depth, purposeful sampling. Sommer and Sommer (2002) (as described in Bezuidenhoud, 2014) indicated that the researcher must specify the sample size in advance in order to avoid allegations that data collection was stopped as soon as study results favoured the hypothesis or research problem. In this study, five breast cancer patients were chosen because they could all relate to specific experiences, behaviours and roles that the researcher was interested in and wanted to explore. All five patients were either busy with breast cancer treatment or finished with the treatment, but still suffering from belated side-effects. They were all able and willing to participate and contribute to the study, which according to Patton (2002) ensured that a good purpose sampling has taken place. Small numbers, as emphasised by Richie and colleagues (2014) will ensure that the sample will be rich in terms of the populations, characteristics and diversity that it represents.

#### **6.3.3.3.2 Data saturation**

Data saturation is discussed in the literature as a point in a study at which the researcher no longer hears anything new, or when the researcher may be aware that he or she is not learning anything new (Lincoln & Guba, 1985; Patton, 2002). As the researcher and therapist, I have felt after the interviews and therapeutic sessions with the five breast cancer patients, that I have gained sufficient information from them regarding the study subject and felt satisfied with the outcome of the interviews and therapeutic sessions.

#### **6.3.3.3.3 Patients selected**

Five breast cancer patients were purposively selected by the researcher of this study on the basis of their potential for providing rich and in-depth descriptions of their breast cancer journey, their willingness to participate in the study and their availability for the duration of the study. Two of the five participants were selected from a government-funded or state hospital which was just diagnosed with breast cancer and started their treatment. Three patients were recruited from the private sector and were already finished with their treatment and in the remission or re-entry phase.

As described in Chapter I, the study participants were referred to as patients because they were, during the research study, actively busy with a psychotherapeutic process (and as a clinical psychologist, come from a background where psychotherapeutic “participants” are called patients). The term patient refers then rather to their psychotherapeutic status as to their cancer status. Academically the terminology of ‘patient’ was associated and used with patients actively busy with breast cancer treatment and ‘survivor’ when the person was finished with her treatment and in remission (Park et al., 2009; Twombly, 2004).

#### **6.3.3.4 Recruitments of the study patients**

- **Patients**

**State Patients:** The reason that I have chosen the two patients from a state hospital was from a practical viewpoint regarding the availability of them during the whole breast cancer treatment. These two patients were acquired at the State hospital’s oncologic department. The decision to include state patients was based on the availability of patients to engage in therapeutic interactions on the days of their cancer treatments in order for the researcher to be able to participate in their whole treatment experience from diagnosis through to the end of their treatment. I also wished to include breast cancer patients from the community who would not be able to see a psychologist out of their own accord either because of a lack of finances or because of a lack of availability of psychological services. During the recruitment process of the state patients, I had to familiarise myself with the working of a state facility and had to obtain ethical clearance from the National and Provincial Health Research & Ethics Committees of South Africa (NHRD) (which will be discussed fully in 6.3.3.5) to involve state patients. After obtaining ethical clearance, permission was granted from the head of oncology to attend a meeting at the state hospital’s oncology ward with a group of newly diagnosed breast cancer patients to meet with the oncology team and possibly recruit suitable candidates for the research study.

During this group meeting that was held in the hospital’s oncology ward with the newly diagnosed breast cancer patients and their families (some of them brought their families with), an oncologist explained what a diagnosis of breast cancer

means and the process of breast cancer treatment that was lying ahead of them, especially concerning surgery and chemotherapy and their probable side-effects. General, practical matters such as the location of the chemo room, consultation rooms, the sister's station, and scheduled dates concerning their treatments were also explained to them. At the end of the session the oncologist introduced me to the group of patients, giving them a brief explanation of the study and asked to consider volunteering if they fit the including criteria. After this introduction I have also presented a short description of my study and described what would be expected of them if they choose to participate in the study and if they fit the criteria. At the end of the session three patients immediately came forward to ask to participate in the study. I then, individually, explained in short the aims and the context of the study and what their roles as study patients would be. An information form was given to them to take home and read through and discuss, if they wanted to, with their families before making a final decision to participate. All three patients who have agreed to participate in the study have complied with the criteria for the study and upon recruitment I made a formal appointment together with their next chemotherapy session which was three weeks hereafter. One week before the first session the patients were contacted by phone to confirm their scheduled appointments and to give them time to ask any questions they might have before our first session. All three of them sounded enthusiastic and were looking forward for the psychotherapeutic sessions to start. After the first session, one of the patients did not come back without giving any reason as to why and I left it at that. The two state patients were called Patient II and III.

**Private Patients:** The breast cancer patients that were included in the study as cancer survivors were all three from the private sector. Two were referred by medical professionals who knew about this study (I have informed a couple of oncologists and psychologists about the study for possible candidates) and one was recruited by the researcher, originally for the pilot study. Patient I was recruited for the pilot study for the main reason that it was believed that she could contribute to the study because of her working knowledge in the medical field and strong understanding of psychology together with her own cancer status. She was also willing and enthusiastic to take part in a study where she could share the



experiences of her breast cancer for the chance of helping other breast cancer patients.

Patient IV is a private patient but did not belong to a medical aid. She wanted to participate in psychotherapy but could not afford to see a psychologist and after hearing of this study from another clinical psychologist, she requested to participate in the study. She was contacted by the researcher and after explaining what the study entails she expressed her willingness to participate. She had a need to see a therapist but also to contribute to the study and help other breast cancer patients through her own experiences.

Patient V requested her oncologist to see a psychologist for treatment and the oncologist, who knew about this study, referred her. The researcher contacted her and explained to her what the study and the process would involve. She was willing to participate in the study for the therapeutic process and also for a chance to share her knowledge of her breast cancer experience. All three patients have complied with the criteria for participating in the study. Only patient I and patient V was in the financial position to afford the services of a clinical psychologist.

The private patients were required to come to the therapeutic sessions on their own time (which would suit both the patient and the researcher) and with their own transport. It was made clear to them that all the therapeutic sessions were for free. After getting their details from the referring practitioners, the three patients were first contacted by phone, where they were given a brief explanation of the study and what the study would entail and what would be expected of them if they decided to participate. They were also given time to ask any questions that they might have concerning the study or their participation therein. During the first telephone contact, their first appointments were scheduled at my practise and at the home of one of the patients (for practical reasons) and the day before their first appointments, it was confirmed again telephonically. The three patients complied with the criteria for the study and understood the purpose of the study and what it would entail for them to participate in the study.

The inclusion criteria were: (a) a diagnoses of breast cancer; (b) the patients could be anywhere in the breast cancer trajectory, from newly diagnosed and at the beginning of their treatment, through to the remission phase (but not in remission

for more than five years); (c) adult women aged between 30 and 65; (d) patients included in the study must live in Cape Town or the Cape Town region for accessibility for the therapeutic sessions; and (e) the patients must be able to speak and read English or Afrikaans to be able to participate in the research survey. There were no limitations in cultural background, marital status, or religious preferences for the women who participated in the study, but the study did not include patients that were terminally ill or were diagnosed with metastatic breast cancer. The appraisal of relevant literature of former research in this field helped to identify characteristics that are known to have an impact on the subject being investigated and should be included as selection criteria or used to define the population for the study (Ritchie et al., 2014).

#### **6.3.3.5 Interview Environment and Therapeutic Time Frame**

- **Interview Environment:**

The term therapeutic environment refers to any environment that has, as its purpose, a therapeutic effect on an individual and a psychologist's office can be regarded as therapeutic because it is designed and decorated with the intent of making patients feel safe and comfortable (<http://www.wisegeek.com/what-is-a-therapeutic-environment.htm#>). According to Pressly and Heesacker (2001) and Wedding (2010) the physical surroundings in the counselling workspace can influence the relationship between therapist and patient as well as treatment outcomes. For the purpose of this study and working with an already traumatized population, it was important for the researcher, also working in the role of a clinical psychologist, to have provided a safe and comfortable space for the research study patients to share their deepest and innermost experiences.

- **Therapeutic Time Frame:**

The amount of therapeutic sessions have varied from six to eight depending on motives such as practical elements, saturation of information and reaching the psycho-therapeutic goals. With the two state patients, the sessions were booked the same day as their treatments because of practical reasons such as distance and transport and with the end of their active cancer treatments they did not have to travel to the hospital anymore. Because of the traveling aspect, the sessions

could not go on beyond the completion of the cancer treatment and therefore it was terminated, but not without reaching the mutual goals. With the completion of their cancer treatment, both state patients felt that they would be able to continue without the psycho-therapy, feeling better adapted and equipped to handle their current breast cancer situation, as well as the chronicity of their illness. With the three private patients, the researcher ended the sessions when the therapeutic process was satisfactory for both patient and therapist. Patient IV was an exception as she requested sessions as a private patient to continue her therapeutic process on a longer term, as soon as her medical aid allowed, for she needed extensive therapeutic interventions because of her long and complicated history of depression. It must also be taken into consideration that there were time limitations on the study.

Time-wise, all of the sessions were between one hour and one hour and thirty minutes. The therapist took Young and Beck's (1980) principals of therapy into consideration, namely that pacing and optimising time are crucial components where the objective should be to accomplish as much as possible during each session, but with considering the capacity of the patient to absorb new information.

At the beginning and end of each session, there was usually a brief feedback phase of the patient's experiences of the last session and the time in between. Most of the time this came spontaneously from the patient, but it was also an aim of the therapist to check on the experience of the patient regarding the therapeutic interventions

#### **6.3.3.6 Ethics**

Regardless of the approach or qualitative inquiry, qualitative researchers are confronted with a number of ethical issues and considerations throughout the research process which must be consciously controlled by the researcher through applying prescribed ethical standards (Creswell, 2007; Flick, 2009; Silverman, 2011). The fundamental principle of research involving human subjects is to protect the well-being and safety of the research participant and to make sure that the research process is not harmful to the participants (Creswell, 2007; Wassenaar, 2006; Yin, 2014). Appropriate ethical thought was given to the study to secure that no harm would be done to any participant as a result of the research

and the researcher has adhered to and acknowledged the ethical responsibility to conduct consequential and reliable research by following the general ethical guidelines of Webster and colleagues (2013) and Creswell (2014).

Permission to conduct the study was granted by the Ethics Committee of the Psychology Department of UNISA on the understanding that:

- Because of the sensitivity of the information being sought and the fact that the participants come from a vulnerable population, it is required that ethical principles related to informed consent, anonymity, confidentiality and the right of participants to withdraw should be strictly enforced.
- Clearance is to be obtained from the hospitals from where the participants are to be drawn, and all conditions and procedures regarding access to patients for research purposes that may be required by these institutions are to be met.
- If any further counselling is required in some cases, the participants will be referred to appropriate counselling services.

Regarding the inclusion of the two participating state hospital patients, ethical approval was also obtained from the National and Provincial Health Research & Ethics Committees of South Africa (NHRD), who serve as the gatekeeper for monitoring and managing health research for the National Health Research Committee, Provincial Health Research Committees and Research Ethics Committees across South Africa.

After gaining the permission of the Ethics Committee of UNISA and the NHRD, the next step in selecting participants was to gain consent from all persons who might be part of the study and to provide them with appropriate information about the contents of the study (Wassenaar, 2006). The researcher clearly explained the objective, purpose and intent of the research study to the five breast cancer patients before starting with the study. The researcher also explained that their participation is voluntary and that they have the freedom to decline or withdraw any time after the study has started without giving any reason or to feel pressurised to continue participating. The five patients were provided with clear, detailed and factual information about the study, its methods, risks and benefits,

as well as the therapeutic interventions, keeping in mind that a participant can only make an informed decision if the information about the study is sufficient (Wassenaar, 2006). I was careful not to have made unreasonable demands on the study patients and there were an agreement between us that they could enunciate any questions or concerns at any given time during the research study. The practical elements of the study, like the scheduled times and place of the sessions and the duration of the interviews, questionnaires and therapy sessions, were explained individually to the patients. At the initial meeting, each participant was given an informed consent document to review and sign. The researcher has obtained both written and verbal consent from all the participants.

Ethical principles are clear that researchers should do everything possible to maintain the confidentiality and anonymity of participants in research (Webster, Lewis, & Brown, 2013). As the researcher, I ensured confidentiality and anonymity through the use of pseudonyms and that no identifiable information was used during the results discussion. The research participants were treated with dignity and respect and appointments were honoured. All the files with their personal details, interviews and questionnaires with the full range of findings will be kept confidential and secure in a locked filing cabinet with access to nobody other than the researcher for at least five years post study, as their information are treated as a typical psychotherapeutic patient who's file must be stored for five years after termination of therapy. I have explained in detail to the participants who have never been in therapy before, what the psychotherapeutic process entails and what they can expect of that. It was also explained to all five patients what sex therapy involves, as it was part of the study process and whether they would feel comfortable engaging in this type of therapy. I have made sure throughout the process that the patients felt valued and respected as people at all times and that after the research process unbiased and accurate reporting would be attempted by the researcher.

I have adapted the ethics guidelines of Webster and colleagues (2013) throughout the research process to protect the study patients and will summarise it in Table 6.3.

**Table 6.3: The ethical framework that was adapted in this study and was applied before, during and after the therapeutic process.**

<b>Before the interview:</b>	<b>During the interview:</b>	<b>After the interview:</b>
<ul style="list-style-type: none"> <li>• The study patients were not pressured in any way into the study. They understood that their participation is voluntary.</li> <li>• They were provided with a consent form to sign after being fully informed what the study is about.</li> <li>• The patients were informed why they were selected for the study and their possible contribution to the study.</li> <li>• The patients have understood the objective, aim and expected intention of the study, as it was explained to them by the researcher.</li> <li>• The patients knew what to expect during the therapeutic sessions.</li> </ul>	<ul style="list-style-type: none"> <li>• The patients were reminded that their participation is voluntary and that they can end their participation at any given time if they wish to.</li> <li>• I have continuously made sure that all five patients felt safe and comfortable at all times.</li> <li>• The patients were given enough time for self-expression and emotional catharsis during the sessions.</li> <li>• The patients were given enough support and reinforcement during the sessions.</li> <li>• The research participants were treated with dignity and respect during all the sessions and all the appointments were honoured.</li> </ul>	<ul style="list-style-type: none"> <li>• To adhere to the responsibility to store the information of the patients at a safe place.</li> <li>• As the researcher, I have tried to be unbiased and accurate in analysing and reporting the data.</li> <li>• I have made sure after the end of the therapeutic process that all the patients were satisfactory (through a last telephonic contact) and that they were permitted to contact me in case of an emotional emergency.</li> </ul>

The consideration and implication of the above means the developing of an ethical conscience that put participants' interests at the heart of decision making, intervention, data collection, management and analysis and reporting the results (Webster, et al., 2013).

#### **6.3.3.6.1 Informed Consent**

The first step in selecting the participants was to gain consent from all persons who may be part of the study and to provide them with appropriate information

about the contents of the study (as explained in Table 6.3), (Wassenaar, 2006). It was imperative for the participant to understand the nature and the aim of the study, that her participation was voluntary and that she had the freedom to decline or withdraw any time after the study has started. This all had to be done in a language that she would understand. The researcher has provided the patient with clear, detailed and factual information about the study, its methods, risks and benefits, as well as the therapeutic interventions, keeping in mind that a participant can only make an informed decision if the information about the study is sufficient (Wassenaar, 2006). The practical elements of the study, like the scheduled times and place of the sessions and the duration of the interviews, questionnaires and therapy sessions was explained individually to the five participants. The consent had to be formalised in writing (Wassenaar, 2006), and each participant had received a letter of consent to sign (see appendix C).

#### **6.3.3.6.2 Privacy and confidentiality**

Ethical principles are clear that the researcher should do everything possible to maintain the confidentiality and anonymity of participants in research. This meant, in practical terms, protecting the privacy and confidentiality of my study participants so that they would not unwittingly be put in any undesirable position (Webster et al., 2013; Yin, 2014).

The research participants were treated with dignity and respect and appointments were honoured. All the files with their personal details, interviews and questionnaires with the full range of findings will be kept confidential and secure in a locked filing cabinet with access to nobody other than the researcher for at least five years post study. I have explained, in detail, to the two participants who have never been in therapy before this study what the psychotherapeutic process entails and what they could expect of it.

#### **6.3.3.7 Strategies for ensuring trustworthiness in qualitative research projects**

Qualitative researchers have developed unique terms that are more fitting to qualitative research such as credibility (reliability), authenticity (validity or trustworthiness), transferability, dependability (constancy) and confirmability (prove) which are the naturalist equivalents for internal validation, external

validation, reliability and objectivity that are the used terms in quantitative research (Creswell, 2007; Koro- Ljungberg, 2010; Lincoln & Cuba, 1985; Morrow, 2005). The concepts of validity, credibility and reliability were originally developed in the natural sciences and then expanded to qualitative science (Lewis, 2015; Richie & Lewis, 2013). Trustworthiness, which include terminology such as credibility, validity and reliability of qualitative research, has been often questioned and challenged by qualitative researchers (positivists) because their views of validity and reliability cannot be dealt with, and applied in the same way in qualitative (naturalistic) work (Shenton, 2004). In the scientific context, trustworthiness refers to the replicability of a study's findings, meaning, if the study gets repeated in the exact manner by a different investigator, would he get the same results again (Richie & Lewis, 2003, 2013). The goal of trustworthiness is to minimise the errors and biases in a study, therefore it is important to thoroughly document the procedures which is a way of dealing with reliability (Yin, 2014). Trustworthiness is a central concept in any discussion of generalisation and is concerned with the strength and credibility of the original research evidence and by implication whether any wider interpretation or suggestion can be sustained (Richie et al., 2013).

Although all research must have truth value, applicability, consistency, and neutrality in order to be regarded as worthwhile, the nature of knowledge within the quantitative paradigm is different from the knowledge in the qualitative paradigm (Guba & Lincoln, 1981; Morse et al., 2002). In dealing with these challenges, several qualitative researchers have demonstrated how qualitative researchers can integrate measures that deal with these issues (Guba, 1981; Koro-Ljungberg, 2010; Morse et al., 2002; Shenton, 2004; Silverman, 2001; Winter, 2000). Guba (1981) has proposed four criteria (that was derived from similar issues employed by the positivists) that should be considered by qualitative researchers in the quest for a trustworthy study.

- Credibility (in preference to internal validity).
- Transferability (in preference to external validity/generalisability).
- Dependability (in preference to reliability).
- Confirmability (in preference to objectivity).



The researcher employed various strategies, as suggested by Shenton (2004) in an attempt to fulfil above-mentioned criteria in this study which included the following:

#### **6.3.3.7.1 Credibility**

Credibility deals with the focus of the research and refers to the confidence in how well the data address the intended focus (Elo, et al., 2014). To ensure credibility in qualitative studies is one of most important factors in determining trustworthiness (Lincoln & Guba, 1985) and the following strategies can be implemented by researchers to promote credibility and validity by accurately documenting the study phenomena (Creswell, 2007; Creswell & Muller, 2000; Shenton, 2004):

- Prolonged and lengthy engagement with the study participants and persistent observation in the field including building trust with the participants is a validation strategy (Creswell, 2007; Lewis 2015; Richie et al., 2013).
- Triangulation, which is a validity procedure, is where researchers search for integration among multiple and different sources, methods and theories to provide supporting evidence and form categories or themes in a research study (Creswell, 2007; Creswell & Muller, 2000; Richie et al., 2014). Triangulation represents a systematic process of sorting through data to find general themes by eliminating overlapping areas through the interpretation of only the researcher (Creswell & Muller, 2000).
- Individual interviews which form the major data collection strategies for much qualitative research.
- Approaches to help ensure honesty in study participants– each participant must be given the opportunity to decline to participate in the study and give enough information to make an informed decision to participate to ensure that all the participants are genuinely willing to take part in the study. Participants should clearly understand that they have the right to withdraw at any given point from the study without disclosing an explanation to the investigator (Shenton, 2004).
- Repeated interview sessions between the researcher and his or her superiors– in this case the study promotor where, through discussion, the

researcher's vision may be widened or changed to alternative approaches (Shenton, 2004).

- According to Shenton (2004) if the researcher uses a reporting system in which he/she defines a series of categories within a typology and illustrates these categories using real qualitative episodes which enables the reader to evaluate how far the defined categories truly embrace the actual situations (Creswell, 2007; Lewis et al., 2014).
- Examination of previous research findings through literature to assess the degree to which the study's results are congruent with those of past studies. The ability of the researcher to relate his or her findings to an existing body of knowledge is a key criterion for evaluating works of qualitative inquiry (Silverman, 2001).

A "valid" account in qualitative research refers to the presentation of an explanation that is sound and grounded in the research information (Cosser, 2009). In spite of the fact that qualitative research is often criticised for not being objective and although there is no distinct or clear validation approach, Creswell (2007) considers validation in qualitative research as an effort to assess the accuracy of the findings as best described by the participants and researcher and which suggests that any account or description of research is a representation by the author. According to Osborne (1994) findings are valid to the extent that they reverberate with the experiences of others who have experienced the phenomenon in question. In Creswell's (2007) viewpoint validation is a definite strength of qualitative research in that the justification is made through extensive time spent in the field and detailed generous description and the closeness of the researcher to the participants in the study which all add to the value or accuracy of the study.

There are authors, such as Wolcott (1990) and Winter (2000) that reject the notion of validity entirely in any form as inappropriate to their work. Wolcott (1990) who has very little use for validation, suggests that validation neither guides nor informs his work because he would rather try to understand than convince. In the light of this, statistical tests or measures of reliability and validity as used in quantitative studies, are wholly inappropriate for qualitative investigation and would cause

confusion if applied (Ritchie et al., 2014). Some authors like Guba and Lincoln (1994) are of the opinion that qualitative research should rather be judged by its authenticity or genuineness which includes whether it has represented a variety of different realities, whether it helped people to develop better and more complex understandings and perceptions, if it can motivate and encourage actions and if it empowers people to change their social circumstances (Ritchie et al., 2014). If the qualitative researcher seeks for validity, it would rather lie in the representation of the case studies (individuals), the purposes of the research and appropriateness of the processes involved (Winters, 2000).

#### **6.3.3.7.2 Transferability**

External validity in quantitative work means that a study's findings must be generalizable beyond the immediate case study regardless of the research method used (e.g. experiments, surveys or case studies) and be applied to a wider population (Merriam, 1998; Winter, 2002; Yin, 2014). Qualitative studies on the other hand, strive more to provide a rich and contextualized understanding of some aspect of the human experience through the intensive study of particular cases, more than to generalize (Polit & Beck, 2010). Another procedure for establishing transferability in a research study is for the researcher to give a rich and detailed description of the participants under study, providing the reader to transfer information to other similar situations and to determine whether the findings can be transferred because of shared characteristics (Creswell, 2007; Lewis, 2015; Ritchie et al., 2014). The process of writing a thick description in terms of information about the setting, the participants and the themes of a qualitative study in rich detail, creates, according to Creswell and Muller (2000) verisimilitude that creates accounts that produce for the readers the feeling that they have first-hand experienced, or could experience the events being described in the study. Denzin (1989) states that the process of using thick, detailed and vivid description is to help the reader understand that the account is credible and enables the reader to make decisions about the applicability of the findings to other settings or similar contexts.

Because findings of a qualitative study are specific to a small number of environments and individuals, it is not possible to generalize the findings and

conclusions to other situations and populations (Shenton, 2014; Stake, 1994). Shenton (2014) urges qualitative researchers not develop a preoccupation with transferability, for ultimately, the results must be understood within the context of the particular characteristics of the group or population, or even the geographical area in which the fieldwork was done.

My hope for this study is that the reader will learn something new and expand their awareness and understanding of the breast cancer patient and survivor by reading this study. This project should challenge, not only psychotherapists working within this population, but also other medical professionals who desire to effectively work with cancer patients. This valuable information should inspire others to learn more about supporting cancer patients in a psycho-therapeutic manner.

#### **6.3.3.7.3 Dependability**

Dependability refers to the stability of data over time and under different conditions. The dependability of a study is high if another researcher can readily follow the decision trail used by the initial researcher, therefore it is important to state the principles and criteria used to select participants and detail the participants' main characteristics so that the transferability of the results to other contexts can be assessed (Elo et al., 2014; Thomas & Magilvy, 2011). In addressing the issue of reliability, the positivist employs techniques to show that, if the work were repeated, in the same context, with the same methods and with the same participants, similar results would be obtained (Shenton, 2004). To enable readers of the research report to develop a thorough understanding of the methods and their effectiveness of the study, it should include the next elements as described by Shenton (2004) and as implemented in this study:

- The research design and its application, describing in detail what was planned and implemented on a strategic level.
- The operational detail of the data gathering in the field.
- Thoughtful assessment of the study and assessing the effectiveness of the data gathering.

#### 6.3.3.7.4 Confirmability

Confirmability is the qualitative researcher's comparable term to objectivity in quantitative research. Confirmability of findings means that the data accurately represent the information that the participants provided and the interpretations of those data are not invented by the inquirer (Elo et al., 2014; Polit & Beck, 2012). For the qualitative study to represent confirmability steps must be taken to make sure that the findings of the work are the results of the experiences and ideas of the participants and not of the characteristics and preferences of the researcher (Shenton, 2004). The role of triangulation in enhancing confirmability must again be emphasised to reduce the effect of investigator bias, as well as detailed methodological description to enable the reader through an "audit trail" to determine the credibility of the data and construct of the study (Creswell, 2007; Creswell & Muller, 2000; Ritchie et al., 2013; Shenton, 2004).

#### Strategies for achieving trustworthiness in this study

Although the researcher has taken all the prescribed steps to make the study as valid and reliable as possible, the aim was predominantly to understand all the aspects of the experiences of the breast cancer patients instead of spending unnecessary energy to perfect the validity and reliability of this study. Table 6.3 gives a description of the practical application of the characteristics of trustworthiness in this study.

**Table 6.3: The practical application of the characteristics of trustworthiness**

CHARACTERISTIC	APPLICATION
<b>Credibility</b>	A detailed description of the methodology and a literature review was conducted including both the psychological and medical aspects of breast cancer, allowing the researcher to give a detailed description of the phenomenon under investigation. This could add credibility as it helped to convey the actual situation and context of the problem.

As the researcher I have developed a familiarity with the participating organisations, the private oncology institutions, state hospital and breast cancer population before conducting the study.

I spent extensive time in the field during the psycho-therapeutic sessions and gave detailed and generous descriptions of the data. The closeness and time spend between me and the patients in the study had also added to the value or accuracy of the study.

I adopted approved research methods such as semi-structured interview questions and observations conducted by myself with 26 years of experience in interviewing and assessing patients in a clinical practise.

I developed lengthy engagements with the study participants through therapeutic sessions over a period of a year, building a trustful relationship for gaining more sensitive information.

I used triangulation through using five breast cancer patients of different ages and stages of breast cancer. Their different viewpoints and experiences were confirmed against each other and a rich and detailed image was formed. Triangulation was also used to have sorting through the data of the 5 case studies to find general themes by eliminating overlapping areas.

The different individual viewpoints and experiences of the participants were verified against one another and against the literature and a full picture of their

	attitudes, needs and behaviour were constructed.
<b>Confirmability</b>	<p>I gave a clear and detailed description of the purpose of the study, a step-by-step illustration of how the data was gathered during the interviews and therapeutic sessions and how the data was processed.</p> <p>The aim of the therapist was for the findings to resonate with the experience of others who have experienced the same phenomenon by giving a very detailed and rich description of the experiences of the five breast cancer patients by using their own voices and generous quotes.</p> <p>Triangulation can also be used in an attempt to reduce investigator bias.</p>
<b>Dependability</b>	The researcher provided an in-depth methodological description of the design of the study, stating the principles and criteria used to select the five patients with detail of the biographical details of the patients.
<b>Transferability</b>	<p>The boundaries of the study were made clear from the onset of the study. As was the number of cases, the variables, data collection methods, including the number and length of the data information sessions, the average length and the time period over which the data was collected.</p> <p>Transferability was addressed by providing a clear goal of the research study, detailed descriptive data, including a comprehensive description of the patient's biographical details and the research design.</p>

	Every step of the research process was documented for the reader to be able to “see” the process from the “inside”.
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**6.3.4 Data collection**

**6.3.4.1 Pilot study**

During the process of data collection in this study, a pilot study was conducted as a final preparation to ensure that the questions selected from the literature to be included in the questionnaire, were clear and sufficiently representative of the field of cancer and cancer treatment (Venter, 2014; Yin, 2003). Kanjee (2006) explains that a pilot study is a preliminary study to conduct before implementing the final research design to identify potential problems with the design, especially the research instruments. Yin (2003) stated that a pilot study will help the researcher to hone his data collection plans regarding the content of the data and the procedures to be followed. Yin made it clear that it is not a pre-test, but more of an influential element to assist the researcher to develop relevant lines of questions. After conducting the pilot study, one of the most crucial changes that I have made, was to change the (much more) formal and lengthy interview questions to more free range questions combining the questions with the therapeutic process, meaning that instead of having different interview sessions and therapeutic sessions, the researcher integrated them. This was essentially because of the time limits of the study and practical considerations (6 to 10 sessions) and the patient’s needs to talk more freely about their cancer experiences and therapeutic interventions. Another reason was that the type of open ended questions that were asked have almost always triggered a lengthy description of their experiences, giving valuable insight into the cancer patient’s life, but also served as an emotional catharsis, which was part of the therapeutic process.

**6.3.4.2 Interviews and direct observation**

- **Interviews**



This study used in-depth interviews to explore breast cancer patients' perceptions of their cancer experience and their need for psycho-oncologic interventions. The researcher who conducted the in-depth interviews is a practicing clinical psychologist who entered the research relationship with the five participants as a professional therapist where years of doing psychotherapy had provided her with professional skills in conducting effective interviewing and psycho-therapeutic skills. Apart from the pilot study, where there were well defined interview sessions with the patient, the researcher preferred to use the term "therapeutic sessions" instead of interviews or interview sessions. The reason for this preference of terminology is that the patients, from the first session, were encouraged to engage in a psychotherapeutic process where they could express their unique cancer experience by answering questions or volunteer information, but also experience psychotherapeutic interventions immediately. The information and the therapeutic process of the pilot patient were so insightful that it was decided to include her in the study as part of the study participants. Considering the in-depth and rich information that this study had generated, I have succeeded in my aim to establish a climate which encouraged trust and self-disclosure from the study patients. The aim of the research study, which is to explore and understand the breast cancer patients experience and needs regarding their cancer and psycho-oncologic interventions, has guided me in asking relevant questions and implementing therapeutic interventions but was also noticed that there was a natural and spontaneous flow of conversations from the very first session regarding sharing their experiences and thus little need for the researcher to engage in a formal interview mode because the patients were very focused on their breast cancer experiences.

The amount of sessions for each patient depended on where the patient was in her cancer trajectory or her need of psychotherapy in terms of her psychological wellbeing and it has varied from five sessions to eight sessions. Five months into the process of emerging and improving the interview- and therapeutic process I started to recruit and interact with four other breast cancer patients which extended over a period of thirteen months. As the researcher, I wish to distinguish between the two patients who were newly diagnosed and just started with their treatment program (chemotherapy) and which were both state hospital patients

and the three patients who were already finished with their treatment and in remission and which were private patients.

Yeo and colleagues (2014) define in-depth interviews as a powerful method for creating description and detailed interpretation of people's social worlds and stresses the importance of talking to people to understand their point of view. Conducting an interview is a natural form of interacting between individuals and is based on verbal communication and spoken descriptions which are essential sources of case study information and fitting well with the interpretive approach of this study (Kelly, 2006; Lewis & McNaughton, 2014; Yin, 2003, 2014). Face to face interacting between participant and researcher is regarded as a core method of qualitative data collection where it gives the researcher the opportunity to get to know his study participant quite intimately and allowing him/her to really understand the depth of the feelings and experiences of complicated constructs or experiences (Lewis & McNaughton, 2014; Yeo et al., 2014). Some authors even see the interview as a guided and purposeful conversation in order to make the interview more fluid and open ended rather than controlled and rigid (Yeo et al., 2014; Yin, 2003, 2014). I supported the view that the value of an interview as a data collection method is grounded in the belief that participants are people who dynamically create their own social worlds and can, through words, communicate insight about this world (Lewis & McNaughton, 2014). Interviews, which are the most apparent way to investigate delicate or complex issues, were used in this study (as part of a psychotherapeutic process) where the study patients could share their perspectives within the context of their personal history and experience of their illness.

Data was gathered in the form of psychotherapeutic sessions which also served as interviews with each breast cancer patient. The length of the interviews was ranged from one hour to ninety minutes, which are more or less the standard time for a psychotherapeutic session. I have found that during therapy sessions, patients often wanted to go over their time especially when they got entangled in their emotions and experiences regarding their cancer. This has obligated the therapist to stay within the scheduled timeframe of the sessions, which were either an hour or an hour and a half. I made it a point at the beginning at each session to

remind the patient of the time of the session and to warn her plus minus 10 minutes before the session ended to wind down and concluded their “stories” or experiences and also used the time to schedule the next session.

Throughout the therapeutic process I aimed to establish a relaxed and trusted atmosphere for the study patients to open up and share their deepest experiences. We engaged in a more conversational style to build rapport than an inquisitorial style. The sessions were also conducted in the participant’s language of choice. During the first interview the aim and the purpose of the study was explained as well as the ethical obligations concerning the study. With all five patients the interview- and therapeutic sessions were very spontaneous in terms of their participation and interactions. After the initial explaining of the interview- and therapeutic process, little encouragement were necessary to have engaged the patients in a therapeutic conversation, for they were open and honest about their thoughts and emotions regarding their breast cancer experience and very willing to talk about this experience. When asking questions during the sessions, open-ended questions were asked regarding their cancer experience or to explore certain key themes of the research subject, or to obtain more information or interpretative experiences regarding a statement that they have made. The sessions were all very flexible in terms of the questions being asked and the therapeutic goals. There were certain goals in every therapeutic session in terms of the themes that the therapist wished to explore. Flexibility allowed the therapist to use follow-up questions to explore responses and to react on related issues raised freely by the patient. The patient was allowed lead the way in terms of her needs of what she wanted to discuss, or express, or needed knowledge about. I found during the sessions that the patients had the need to talk freely and openly about their emotions and experiences regarding their cancer experience.

The general interview guide used for the interviews were discussed in Appendix A

- **Boundaries and roles in in-depth interviewing when the researcher doubles as the therapist**

According to Dickson-Swift, James, Kippen and Liamputtong (2006) some aspects of qualitative research interviews are strikingly similar to aspects of therapeutic

interviews. An example of this is empathy and listening skills are important for both research interviews, especially qualitative interviews on sensitive topics, and for therapy interviews. In this research study, the researcher fulfilled both the roles of the researcher, in conducting the research process and analysing the data, and as a therapist doing the psychotherapy or therapy interviews. As acting in the dual role of both the researcher and therapist, I have kept in mind the importance of defining and managing the boundaries between researcher/therapist and the patients while conducting the study (Dickson-Swift et al., 2006). Yeo and colleagues (2014) said that a practitioner-researcher needs to understand and take into account their own professional codes which will differentiate from other researchers.

One of the advantages in acting in the dual role of the clinical psychologist and researcher was that I could develop a close patient–therapist relationship and lengthy interaction with the participants resulting in being able to have observed and gained in-depth material directly from them. Because therapists hold a very special position in the lives of their patients (Bourdeau, 2000) as their therapist and researcher I could observe their pain, but simultaneously also gave them compassion and hope during their trauma and challenges. I have shared the vision of Bourdeau (2000) that in this postmodern era, both therapy and qualitative research are striving to empower the persons who choose to participate in a study and that my work will make a difference and benefit the participants above all else. I have also aimed, in this dual relationship, to stay in contact with the context of the study and how my questions were presented during therapeutic sessions and consciously remained empathetic and understanding during the sessions. As acting in both the capacity of the therapist and researcher, I had the opportunity to have observed the patient’s behaviour in the ‘real time’ of her current situation.

### **6.3.5 Quantitative measures**

#### **6.3.5.1 Combining qualitative and quantitative methods**

Qualitative and quantitative researchers base their conclusions on different kinds of data and utilise different techniques of data analysis. Quantitative methods focus on the strict quantification of data and on controlling of empirical variables (Grieger, 1999; Ponterotto, 2005). Quantitative researchers collect data in the form

of numbers and use statistical types of data analysis, where qualitative researchers collect data in the form of written or spoken language or observations and analyse the data by identifying and categorising themes. Combining qualitative- and quantitative methods is to regard them as equal but also separate and capable to answer different questions about the same topics. These combined methods can be applied where the study requires measurement of some kind (quantitative method), but also deeper understanding of the nature of an issue (qualitative method) (Ormston et al., 2014). This study relies more on qualitative research to obtain rich, detailed information from the cancer patient through face-to-face interaction between the study participant and the researcher, than on psychometrics, which can suppress the spontaneity of the participants' experience. The researcher used a combination of these two methods by applying two standardised questionnaires together with the qualitative information methods, to gather data regarding depression and anxiety and sexual functioning in the breast cancer population.

Ormston and colleagues (2014) explain that mixing the two methods is to see them triangulating each other, which means that they describe social phenomena from different perspectives, where each perspective testing and adding to or validating the other. These authors say that the “safety” in using multiple methods provides a fuller picture of the phenomenon being studied, but not necessarily a more definite one. Two of the primary strengths of quantitative research are that the findings are generalizable and that the data are objective (Terre Blance et al., 2006). When these two approaches are used together they can present a powerful resource to inform and provide clarity about the subject of study.

This study made use of both qualitative and quantitative measures during data collection. This process of triangulation produce a more complete picture as measuring something in more than one way increases the likelihood or seeing all aspects of it (Ormston et al., 2014). I have used two standardised questionnaires as part of the quantitative method.

- **The Hospital Anxiety and Depression Scale (HADS)**



The HADS was developed by Zigmond and Snaith in 1983 (Zigmond & Snaith, 1983). The aim of this brief self-rating scale is to provide clinicians with a reliable and valid practical tool that is easy to use, for classifying and quantifying depression and anxiety (Michopoulos et al., 2008). According to Herrmann (1997) the role of the HADS is more dimensional than categorical, using the scale to identifying general hospital patients who need further psychiatric evaluation and assistance rather than making a diagnosis of psychiatric disorders.

The scale include two different subscales of seven items each, one for depression and one for anxiety and the sum of these tow subscales corresponds to a total score (Montel, 2010; Valdaninia et al., 2010). It has been recognised as a much applied and convenient self-rating scale instrument for both anxiety and depression with both somatic and mental problems and has also been validated in cancer populations (Costanini, 1999; Michopoulos et al., 2008; Moorey et al., 1991).

- **The Female Sexual Functioning Index (FSFI)**

As previously described, female sexual dysfunction (FSD) is common among women who have survived cancer, and the most frequently used instrument to assess sexual functioning in this population is the female sexual function index (FSFI) (Baser, 2012). The FSFI is a 19 item inventory test and is divided into six elements: desire, arousal, lubrication, orgasm, satisfaction and pain (Rosen et al., 2000; Sheridan, 2006). Although the FSFI was originally developed and validated in healthy women, results in a study done by Baser in 2012, indicate that this scale is a reliable and valid instrument for measuring levels of sexual functioning and cancer-related FSD in the cancer population. Baser (2012) found that thorough psychometric properties of the FSFI among cancer survivors were clearly evident in their study, and however subtly, the results also suggest that emotional intimacy with a partner may play a significant role in the sexual functioning of cancer survivors that is conceptually distinct form overall satisfaction with sexual life.

### **6.3.6 Creating a case study database**

#### **6.3.6.1 Case study notes**

Data in this study was obtained through deep, detailed, first-person accounts from the research patients during therapeutic sessions, where analysis was based on a common set of qualitative principles which included the writing down of the 'interviews' during the therapeutic sessions in detail and the process of familiarising the data in an attempt for the researcher to have gained insights in the experience of breast cancer (Creswell, 2007; Smith & Firth, 2011; Smith et al., 2013). The purpose according to Terre Blance and colleagues (2006) is not to collect portions of real life, but to place real-life experiences and phenomena into some kind of perspective which shared the aim of this study.

Handwritten notes were the original raw data and the core component of this research study and were obtained during the interviews and psychotherapeutic sessions with the five breast cancer patients. As described earlier (6.3.6.1) the sessions with the study patients were combined between "interview" sessions and psychotherapeutic sessions. The researcher prefers to call it therapeutic sessions. Even when asking questions during the therapeutic sessions regarding the research subject, it was still 'therapeutic' in the sense that through answering it, it 'doubled' as emotional catharsis for the patient could use it as emotional expression. With all five patients the first session was used to introduce the study and explained the therapeutic procedure. The patients were then asked for a detailed history of their cancer experience or any information that they felt they would like to share whether it was related to the cancer or not. It was explained to, and understood by the patients, that although there were psychotherapy involved, it was still firstly a research study that needed certain questions and answers which had to be written down. After every session the handwritten notes were immediately typed by the researcher in very precise detail to allow for true and detailed descriptions of the interactions with the patients and to have captured observations and detail of the sessions. I used quotations from the breast cancer patients to demonstrate important points (Seidman, 1991). The information was then stored in computer files.

The observations, and questions and therapeutic process were all written down as in 'usual' therapeutic notes, meaning there was not a different set of notes for questions asked and therapeutic interventions. I took the advice of Yin (2014) and made sure that the notes (both handwritten and the computer files) were organized, complete and available for later access during analysis process, especially because it was such a long process and many sessions which meant that I had to rely very heavily on my notes for information and detail. This process of getting information, writing it down during the therapeutic sessions and transcribing it after the sessions and organise the data into paper files or computer files is called data management, which count as the first step in the data analysis process (Creswell, 2007; Terre Blance et al., 2006).

#### **6.3.6.2 Tabular material**

Materials such as surveys or structured questionnaires should be organized and stored as part of the above mentioned database (Yin, 2003). In this case the HADS and the FSFI were completed by the patients after the first session. The questionnaires were explained to them during their first official session and it was given to them to take home together with the information- and consent form to study and discuss with their family or partner and to be brought back the next session. All five brought it back with the second session. The questionnaires were marked immediately upon arrival and were filed and stored with the hand written notes.

#### **6.3.7 Interpretive analysis of case study data**

According to Doody and Noonan (2013) and Rabionet (2011) in certain circumstances written notes are preferable to audio recordings due to the fact that in some cases, especially when asking questions regarding a sensitive or traumatic subject, patients tend to be less comfortable and more formal when being recorded. Because it was my aim to gain in-depth information from the study patient on a tough and sensitive matter, I have preferred to keep the interviews very therapeutic and not engaging in anything that could jeopardise a therapeutic environment.



The transcription of the information of the five participants were done immediately after completion of each individual interview and interaction in an attempt to acquire a general understanding of what the patients experienced and expressed regarding their breast cancer phenomenon during the particular session. The basic and most important information was written down in order to remember the details. According to Patton (2002) it is difficult to respond properly to patients/participants' cues when trying to write down every word they said. This author also caution the interviewer that taking verbatim notes can interfere with listening attentively to what the patient says and that the participant then will only get secondary attention. Patton said that qualitative researchers during interviews listen through a 'lens' causing the researcher to be far more present in his or her handwritten notes than would be the case in a verbatim transcriptions or audio-recordings.

Once all the interviews and therapeutic interactions were fully transcribed, I engaged in a process where the data was read and re-read in order to obtain a holistic view of the data. During this process I developed a series of interconnected stages enabling me to move back and forth across the data until a clear description emerged leading to the development and refinement of a set of themes that was part of a set of initial- and refined categories. This was accomplished by the systematic classification system underlined by the thematic analysis method (as described in 6.3.8) and these themes and categories will be fully described in 7. 6.

The interpretation of the data was influenced by the social constructionist data analysis method which focused on interpreting the lived experience of the participants in the breast cancer context and allowed the researcher to find significant themes within the text (Ryan & Bernard, 2003; Sprenkle, & Piercy, 2005). Central to interpretive analysis is for the researcher to provide a transparent and detailed description of the data which can be defined as a thorough explanation of the characteristics, developments and surroundings that represent the experience of the phenomenon being studied. This will not only enhance the trustworthy analysis of the evidence, but also generate alternative debates on the phenomena being researched (Burr, 2003). In practise this has

demonstrated to be a circular process rather than a fixed linear process (Creswell, 2007), which involved careful reading and familiarising of the data from the early stages of the interaction with the breast cancer patients and locating and developing categories and themes to help the researcher make comparisons or identify connections between themes (Basit, 2003). I have often made use of “in vivo” concepts as described by using the participants own language or “voice” and then interpreted the data to make sense of the concepts and themes in terms of the participants’ lives and experiences. I have tried to remain true to the descriptions of the participants while developing more abstract concepts in analysing the data (Ponteretto, 2010; Smith & Firth, 2011).

I was committed to responsibly develop and interpreted themes in the study. I used theoretical principles as guidance to analyse the data and then present the findings in a written report which included the voices of the breast cancer patients. Even though I have used the participating patients own voices on their unique experiences of their cancer journey, the themes would to some degree be influenced by my perception and interpretation of the meaning of them (Dockery, 2014; Finlay, 2011).

#### **6.3.7.1 Theoretical background**

Unlike with quantitative analysis, there are no clear definitions for analysing qualitative data, but researchers can choose from different approaches or methods. The interpretive analysis method, which was used as the foundation for this study, included elements of thematic content analysis and the framework, and phenomenological approaches (Smith & Firth, 2011; Spencer et al., 2014; Terre Blance et al., 2006; Yin, 2003), which will be described briefly here:

- **Thematic content analysis:** This is a subjective interpretation process where data is systematically searched to identify patterns or themes within the data in order to provide an informative description of the studied phenomenon leading to the development of meaningful themes without openly developing theory (Ormston et al., 2013; Yin, 2003). The aim of thematic content analysis is to provide deep and rich knowledge and insights of the phenomenon under study (Neuman, 2003; Smith & Firth, 2011) which was applicable in this study.

- **The framework approach:** This approach enables the researcher to systematically explore data in depth and is well suited to the analysis of cross sectional descriptive data causing different aspects of the phenomena to be captured (Ritchie & Lewis, 2003; Smith & Firth, 2011). This approach also allows for searching and identifying patterns and themes during the early stages of the analysis process to provide informative description of the subject of study. Both approaches attempt to make the process of data analysis transparent and showing the connexion between the stages of the analysis (Richie & Lewis, 2003; Smith & Firth, 2011). One of the core elements of analysing within the framework approach is developing a series of interconnected stages which enables the researcher to move back and forth across the data until a clear description emerges which results in a refinement of themes that can lead to the development of a conceptual framework (Ayres et al., 2003; Ritchie & Lewis, 2003). This was a very prominent process during the study, because there were voluminous information from thirty-two sessions over a period of one year, the researcher had to developed different stages and sub-text and categories and themes and through reading and re-reading it and moved back and forth across the data, it was possible to develop a conceptual framework.

- **Interpretative phenomenological analysis:** The researcher incorporated this approach because of its particular psychological interest in how people make sense of major life experiences. From a phenomenological lens, I have aimed to examine the lived experience of the breast cancer patients in detail and analysed the data to understand the meaning that the breast cancer patients gave to their experience of cancer (Smith et al., 2013).

#### **6.3.7.1 Interpretive analysis of this study**

The choice of using interpretive analysis was influenced by social constructionism which was the guiding epistemology of this study. The methods of interpretive analysis allowed the researcher to have focused on interpreting the lived experience of the study patients in the breast cancer context and to provide a thick and detailed description of the complete breast cancer experience during and after active treatment (Ryan & Bernard, 2003; Sprenkle, & Piercy, 2005). As the researcher I have used the voices of my breast cancer patients to explain their

own unique experiences and perceptions with their families throughout their breast cancer journey and their psycho-oncologic needs that developed out of this journey.

In interpreting the data, I used Creswell's (2007) framework of general data analysis strategies specific to case studies, including:

- Sketching ideas: where the researcher must highlight certain core information in notes and draft a summary sheet.
- Developing core categories and sub categories.
- Reducing codes to themes and identify patterned regularities.
- Relating categories to analytic framework in literature, meaning contextualizing in framework from literature.
- Displaying the data. Display findings in tables, charts, diagrams and figures and compare cases.

The beginning of the process of analysis has already started early on in the research study with the taking down of notes during every therapeutic session and transcribing them over afterwards which involved careful reading and re-reading of the sessions to get familiarised with the data. The five cases were written up separately and independently as explained by Patton (2002). This author reminded the qualitative researcher that when studying multiple cases, each case in the beginning, must be treated as a unique entity with its own individual meaning and patterns developing from and related to the framework within it occurs. One of the aims of this study when analysing the data, was to fully understand all five individual patients before combining them thematically (Patton, 2002). Because of the therapeutic relationship between the therapist and the patients, there was a deep and personal understanding of every patient regarding the meaning and patterns within every case. The process of analysis and interpreting has then continued with making notes in the margins of the original data and then started to break down the data, first in brackets of large chunks of data and then in groups or sub-text (de Vos, Strydom, Fouche & Delpont, 2005;

Ryan & Bernard, 2003). The sub-text were then explored and developed in categories or codes which involved applying labels to chunks of data considered to be about the “same thing” and to help that similarly labelled data can be further analysed (Basit, 2003; Ormston et al., 2014). This process was done from moving from one psychotherapeutic session to the next. Through this, a general system of core categories has developed which was used throughout the documents and the identifying of how they related to one another (de Vos et al., 2005). The categories have helped me to search for similar and related parts of data and developing themes to help comparisons or identify connections between the themes (Basit, 2003). This early organisation of data was referred to as indexing and sorting (Ritchie, & Spencer, 2002; Richie et al, 2013). The content categories were then matched across the different cases to identified common themes that occur in the text or matched and contrasted with other opinions or expressions, for example, the literature (Ryan & Bernard, 2003). In practise, when engaging in the data gathering and analysing process, it is a definite circular process evolving from careful reading and re-reading the transcripts in their entirety and trying to get a sense of the interviews as a whole before breaking up in parts (Creswell, 2007). This is called the abstraction and interpretation stage. In naming the categories and themes, I have used concepts and technical terminology from the psychology and oncology discipline (Basit, 2003).

From the data of the psychotherapeutic sessions, the first chunks of data were organised in two core categories, namely the biological and psychological side-effects of breast cancer treatment and the psycho-therapeutic interventions. From the biological and psychological side-effects of breast cancer treatment, eight sub-categories have developed, namely, (1) the diagnosis of breast cancer; (2) interaction and relationship with the oncologist and medical team; (3) breast cancer treatments: surgery, chemotherapy and radiation; (4) the emotional and practical experience of the cancer journey during and after treatment; (5) sexual functioning due to breast cancer and breast cancer treatment; chemotherapy, surgery and hormonal therapy; (6) work functioning; (7) social support: family system; (8) from breast cancer patient to breast cancer survivor. Developing from these categories were ten themes describing and explaining these categories (which will be fully described in Chapter VII).

I have “clustered” all the emotional, biological and practical categories and themes together that had to do with the breast cancer experience of the patient. The sexual side effects were kept grouped together, for the reader to be able to distinguish between the sexual side-effect and the “non-sexual side-effects. This was also the method with the intervention categories. The next categories and themes have developed resulting from the intervention component of the data resulted in seven sub-categories:

- (a) Emotional catharsis;
- (b) Psycho-education;
- (c) Cognitive and behavioural therapy;
- (d) Sex therapy: talking about sex;
- (e) Sex therapy: psycho-education and behaviour and cognitive techniques;
- (f) Couples and sex therapy;
- (g) Patient feedback.

Developing from these categories were eighteen themes describing these categories in detail that will be discussed in Chapter VII.

The final stage of this qualitative research process involved the explanation of the data through the presenting categories and themes and the presenting of the findings in a written report which has included the voices of the participants through the in depth description of the data and the reflexivity of the researcher, an account and interpretation of the problem and its contribution to the literature or a request for change (Creswell, 2007, 2013). As the therapist and researcher I have understood that reporting a qualitative study is a functional illustration of the phenomenon that was being explored in this study (Holdford, 2008; White et al., 2014) therefore I have included a detailed and extensive representation of the methodology, as discussed in this chapter and the findings and implications from the research. The reporting of the cases and the conclusions will be fully discussed in Chapter VII in the form of written accounts with the aim to present the findings in an accessible form that will satisfy the research objectives and engage the reader (White et al., 2014).

## 6.4 SUMMARY

The aim of this chapter was a discussion of the research methodology that was followed in this study. To better understand the breast cancer patient's lived experiences and their unique need for psycho-oncologic interventions to live a life of maximum quality within the constraints of their illness, qualitative research was explained as the researcher's chosen research paradigm. Within the framework of a multiple case study design, the five patients were purposefully selected from the breast cancer pool where they, upon selection, willingly agreed to have participated in the study. Appropriate ethical thought was given to the study to secure that no harm would be done to any participant as a result of the research and consent from all the appropriate gatekeepers were obtained. Strategies for ensuring the trustworthiness in this qualitative research project were next discussed under the headings of credibility, confirmability, dependability and transferability. The fact that the researcher has also acted as the participating psychotherapist has benefitted the study in the sense that the researcher could "enter" the emotional world of the breast cancer patient through a close and personal relationship over a period of time from where she had the opportunity to have observed and captured the breast cancer patient's experience in the 'real time' of her current situation.

The interpretive analysis method was explained in the framework of the social constructionism, which was the guiding epistemology of the study. The methods that the researcher has covered here were content analysis and the framework- and phenomenological approaches which have led to the development of categories and themes allowing me to have interpreted the lived experience of the study patients in the breast cancer context, providing a detailed description of this phenomenon. I hope that the results of the analytic and interpretation process will provide the oncology clinicians with a deep and rich description of the experiences and needs of the breast cancer patient, including their psychological and sexual effects. By offering a richer and deeper understanding of the breast cancer patient's unique experiences of their illness and survivorship, the therapist hopes that oncologists and psychologists will gain a deeper insight when working therapeutically with this population.





# CHAPTER VII

## FINDINGS

### 7.1 INTRODUCTION

In this chapter the researcher will illustrate the research findings by bringing together the voices of the five breast cancer patients and survivors and the literature to explain and compare them for the sake of generating new insights to a deeper and better understanding of this unique population in order to, in a holistic manner, facilitate support and interventions to better their overall quality of life. The results were developed using a combination of qualitative analytical procedures and the results of the two quantitative questionnaires filled in by the participants as was described in Chapter VI. Regarding the analytical procedures, an attempt was made to stay true to the core ingredient of interpretive analysis, which is staying close to the data and interpret it through empathic understanding and then providing a rich description and explanation of the phenomenon being studied (Terre Blance et al., 2006). In a more practical manner, the researcher has given the participants a voice to explain their own unique experiences and perceptions and needs during their cancer journey (Robertson, 2009).

### 7.2 PARTICIPANT DESCRIPTION

The participants in this study were five women who were diagnosed with breast cancer and were selected on the basis of their first-hand experience of the phenomenon in question. Two of the women were newly diagnosed and at the very beginning of their treatment and the other three, already finished with their treatment and in remission. The remission periods varied from three months to eighteen months and were estimated from their last treatment date or upon clear test results up to our first session. The two patients that were newly diagnosed and still busy with active treatment were both state patients and the other three were from different private practises. The three private participants were identified and referred or recommended by somebody in the oncology- or psychology circles who knew about this study and the two state patients were recruited by the researcher through the hospital's oncology department. The five patients were all

voluntary participants, willing to participate in the study and share their experiences. At the time of the study, only two of the five women had access to a medical aid that made provision for psychology services. The ages of the participants ranged from 34 to 63 years. Four of the participants were married with children, ranging from young children to adult children and one couple was in a long, permanent relationship, they had no children. The researcher will introduce the five study patients through a short summary and will then discuss and present each data category and theme offering examples from the psychotherapeutic sessions. To protect the identities of the five participants their names will not be used, but were replaced by a number allocated to them from I to V, and they were referred to as Patient I to Patient V.

### **7.2.1 State patients vs. private patients**

- **State patients:**

Two state patients, (they were called Patients II and III) who met the requirements of the research study, were accepted and included as participants due to their active undergoing of breast cancer treatment and their willingness to participate in a psychotherapeutic process and to share their experiences with me. They both confirmed that they understood what the study process would entail. For the convenience of the patients all the therapeutic sessions was scheduled on the same day and in the same building as their current treatment (either chemo or radiation or an appointment with their oncologist) and the sessions were for free. A short description of them follows:

Patient II was a 52 year old coloured woman who was diagnosed with stage II breast cancer four months earlier. She had been married for 32 years and had two grown, married children. Although she stayed at home, she had a tertiary diploma in business. At the time of our first appointment she had already undergone a lumpectomy and removal of some lymph nodes and had just started with her first chemotherapy. She did not have a history of depression or anxiety and seemed a content and relaxed person, looking forward to participate in the study.

Patient III was a 63 year old coloured woman who was in her second marriage. She had two grown-up children and had recently resigned from her job because of

its physical demands. She was diagnosed with breast cancer four months earlier and was busy with her first chemo when she was recruited for the study. She presented with problems, emotional and marital, before the breast cancer diagnosis and was very open to participate in the study to be “helped” with her problems.

- **Private patients:**

The three private patients (they were called Patients I, IV and V) had already completed their breast cancer treatment and was in remission. They volunteered to participate in the study after they were referred or it was recommended to them. The details were explained to them, and their appointments were made at the therapists practise and at the home of Patient I. The sessions were scheduled at times that were convenient for them. They were fully informed about what the study would entail and they were all committed to participate in and contribute to the study.

Patient I was a 47 year old Caucasian woman who was 45 years old when she was diagnosed with Stage II breast cancer. She was married and had two young children. She had a lumpectomy and breast reconstruction surgery and had been in remission for 15 months when we started with the therapeutic sessions. She was well known to me and was recruited for the pilot study because of her experience with breast cancer and the fact that she was already in remission. The main reason for including her was her working knowledge and training in the medical field and strong understanding of psychology. She was also willing and enthusiastic to take part in a study where she could share her experiences of her breast cancer for the chance of helping other breast cancer patients.

Patient IV was a 49 year old Caucasian woman who was diagnosed 9 months earlier with Stage II breast cancer. She was in a long-term relationship and had no children. She had a university degree and a higher diploma and was in a full time job. She was a private patient but did not belong to a medical aid and wanted to participate in psychotherapy even though she could not afford to see a psychologist. After hearing of this study from another clinical psychologist, she

requested to participate in the study and was referred. She expressed her willingness to participate in the study because of her need to see a psychologist.

Patient V was a 34 year old Caucasian woman, who had been married for five years, with one child of four years old. She had been diagnosed with breast cancer stage II, two years prior to the study. She had a matric as well as a higher diploma and was in a full time job. She had requested her oncologist to refer her to a psychologist and the oncologist, who was familiar with the study, had recommended that she participate in the study. She was contacted by the researcher and after it was explained to her what the study and process involved, she was willing to participate in the study for the therapeutic process and also for a change to share her knowledge of her breast cancer experience with other women in the same situation. All three patients complied with the criteria for participating in the study.

The complete psychotherapeutic sessions of the research participants, plus their biographical information are presented in the Addendum.

A summary of the demographic information and breast cancer stage and treatment of each patient is presented in Table 7.1.

## **7.3 CATEGORIES AND THEMES: THE VOICES OF THE PARTICIPANTS**

### **7.3.1 Presentation and interpretation of the themes**

Analysis of the data through interpretive- and IPA analytic methods was gathered into categories first and then into developing themes disclosing the biological and psychological effects of breast cancer and the psycho-oncologic needs of, and interventions for the breast cancer patient. The researcher has separated the themes and categories in two parts, the biological and psychological effects and experiences of breast cancer which will be listed in Table 7.2 and the psycho-oncological needs and interventions which will be listed in Table 7.3. The contents and results of the themes that emerged from the therapeutic sessions with the patients will be discussed below the relevant tables and portray the true experiences and interpretations of the breast cancer patients. Several of the themes overlay and intersect each other because the different elements in

experiencing breast cancer are so close together and influence and complement each other in such a way that no major adjustments to the themes were made, but were rather accommodating of the natural and spontaneous flow of the conversations and sharing from the patients. The descriptions of each theme were based on the information given by the study participant and interpretation by the researcher, integrated with existing literature to form a unit between the patient, the researcher and the literature.

**Table 7.1: Summary of patient's detail**

<b>Participant</b>	<b>Age</b>	<b>Marital status and children</b>	<b>Education</b>	<b>Type of breast cancer</b>	<b>Treatment</b>	<b>Busy or Finished with treatment</b>
<b>Patient I</b> Private Pt. Recruited for study by researcher.	47	Married, 2 children, ages 16 and 12.	Gr. 12. University and master's degree	Stage II breast cancer. Progesterone +	Lumpectomy, removal of all the lymph nodes, chemo (8), radiation (32) and hormonal therapy. Breast reconstruction.	Finished 18months Full remission
<b>Patient II</b> Recruited from state hospital by researcher	52	Married, 2 children, ages 21 and 31	Gr. 12. Post matric diploma	Stage IIB breast cancer. pT1cN1M0	Lumpectomy, then radical mastectomy of right breast, removal of lymph nodes, chemo (8) and radiation (15 from 23). No breast reconstruction	Busy with radiation
<b>Patient III</b> Recruit from state hospital by researcher	63	Married, 2 children, ages 35 and 38	Gr. 10 and extra qualification	Stage IIB breast cancer. T3N0M0	Lumpectomy, removal of lymph nodes, chemo (8) and radiation (15 from 23) No breast reconstruction	Busy with radiation
<b>Patient IV</b> Private Patient referred by clinical psychologist	49	Long-term relationship	Gr. 12. Post matric university degrees (including a Honours degree)	Stage III Invasive Duct Carcinoma.	Lumpectomy and removal of lymph nodes, chemo (12) and radiation (30)	Finished 3 months Full remission
<b>Patient V</b> Private Patient asked oncologist to be referred to a psychologist for therapy	34	Married, one child, age 4	Gr. 12. Post matric diploma.	Stage IIA Ductal Carcinoma. Oestrogen + pT2N0N0.	Double mastectomy and complete hysterectomy, chemo (6), radiation (15). Breast reconstruction	Finished 6 months. Full remission

To assist the reader in understanding the themes, and to highlight the unique experiences of the patients, their words, when used, has been italicised.

Analysis of the data was gathered into categories and was then refined into themes disclosing the biological and psychological effects of breast cancer and breast cancer treatment which will be discussed in Table 7.2 and consists of themes 1 to 10 and the psycho-therapeutic interventions which will be discussed in Table 7.3, consisting of themes 11 to 21.

**Table 7.2 The Biological and Psychological Effects of Breast Cancer as experienced by the patients**

CATEGORY	THEMES
<b>The diagnosis of breast cancer.</b>	<b>Theme 1: Emotional reactions directly after hearing the diagnosis and the busy schedule of cancer treatment</b>
<b>Interaction with the oncologist and medical team</b>	<b>Theme 2: Inter-relationship with oncologist and medical team: Receiving information and communication regarding the cancer and cancer treatment.</b> <ul style="list-style-type: none"> <li>• Suggestions from the oncologist/surgeon to consult with a psychologist</li> </ul>
<b>Breast cancer treatments: surgery, chemotherapy and radiation</b>	<b>Theme 3: Biological side-effects on the breast cancer patient:</b> <ul style="list-style-type: none"> <li>• Chemotherapy: <ul style="list-style-type: none"> <li>Fatigue</li> <li>Cognitive impairment</li> <li>Nausea and vomiting</li> <li>Alopecia</li> <li>Pain</li> </ul> </li> <li>• Radiation</li> <li>• Surgery</li> </ul>
	<b>Theme 4: Psychological side-effects on the breast cancer patient:</b> <ul style="list-style-type: none"> <li>• Chemotherapy and emotions</li> <li>• Feelings of depression and the diagnosis of depression throughout the trajectory of cancer treatment</li> <li>• Anxiety and anticipation anxiety</li> </ul>

<b>The emotional and practical experience of the cancer journey during and after treatment</b>	<b>Theme 5: The need to talk about emotions:</b> Specific emotions <ul style="list-style-type: none"> <li>• Guilt feelings</li> <li>• Fear of death</li> <li>• Losses</li> </ul>
<b>Sexual functioning affecting by breast cancer and breast cancer treatment: chemotherapy, surgery and hormonal therapy.</b>	<b>Theme 6: Sexuality and Sex</b> <ul style="list-style-type: none"> <li>• Discussing sexual functioning with the oncologist/medical team</li> <li>• Changes in sexual functioning and losses due to the treatment</li> <li>• Sexual communication and intimacy in the relationship</li> <li>• Self-Image</li> </ul> <b>Theme 7: The Menopausal Factor: The breast cancer patient's experience of it.</b>
<b>Work functioning</b>	<b>Theme 8: Working or not working while receiving chemotherapy</b>
<b>Social support: family system</b>	<b>Theme 9: Effect of breast cancer on the family and marriage</b>
<b>From breast cancer patient to breast cancer survivor</b>	<b>Theme 10: Breast cancer as a chronic disease: the patients understanding of it:</b> <ul style="list-style-type: none"> <li>• The shift from cancer patient to "normal" person again.</li> </ul>

The researcher has distinguished between Patients II and III, the two state patients which were both still busy with their active treatments, (they will be described together) and Patients I, IV and V, the private patients which were already in remission, and which will be described together. The reason for this is that there is a difference in experiencing and describing the cancer and cancer treatment when you are actively busy with it and when you describe something that has already happened. There are also experiences, such as the chronicity of the illness and belated reactions that the active patients do not experience as in yet.



### 7.3.1.1 THE DIAGNOSIS OF BREAST CANCER

#### **Theme 1: Emotional reactions directly after hearing the diagnosis and the busy schedule of cancer treatment:**

Literature defines cancer as one of the most stressful and traumatic medical diagnoses that a person can receive (Meier, 2010; Reyes-Gibby et al., 2012) and all five the patients stated that they were shocked and traumatised the moment that they heard about their cancer diagnosis. Although all of them already expected a cancer diagnosis or a diagnosis of some sort after feeling the lump or underwent procedures to confirm the diagnosis, they were still overwhelmed upon hearing that it was breast cancer. They all agreed that their families were also shocked and confused and not knowing what to say or how to support them in the time immediately after the diagnosis.

*Patient II* said that by the time she had her appointment with the oncologist “*I was so anxious and stressed due to the waiting for the diagnosis and appointment, that the oncologist immediately referred me to their social worker for counselling.*”

*Patient III* said “*I felt devastated when I heard the news and my immediate thought was that I was going to die, in fact, that was all I was thinking about, dying. I was very shocked and scared and not just for that day, but for a couple of days afterwards*” saying that she will never forget the date that she heard the diagnosis “*I only took it one day at a time because I didn’t know what else to do or where to go to.*”

*Patients I, IV and V*, through looking back, confirmed that from the moment of diagnosis, everything went extremely quickly and that they experienced the cancer from the beginning as a busy illness which contributed to their feeling of devastation and being overwhelmed.

*Patient I* said: “*I was so traumatised and shocked that I felt momentarily dissociated from myself and dizzy and nauseas*”.

*Patient IV* said: “*everything started so quickly from when I felt the lump in my breast, it felt that everything just snow-balled with no stopping in between for catching my breath.*”

She also said that, from the very beginning of the diagnosis, she was scared and afraid and had anticipatory anxiety because of her fear of needles and because of her history of depression, she said:

*“I knew after the diagnosis that I should see a psychologist but did not have the finances to do so and just lived ‘robotically’ on a daily basis with my fears and uncertainties.”*

Research has supported this by stating that cancer and cancer treatment are chaotic and busy periods in a patient’s life and that from the beginning of the diagnosis of breast cancer, this disease involves a long process of psychological and social adjustments (Henselmans et al., 2010; Travado & Reis, 2010).

*Patient V* said that the experience of being diagnosed with breast cancer was so overwhelming and everything happened so quickly that she couldn’t think about anything else. She felt that she was not able to participate enough in the decision making process of her treatment. She said:

*“That although my surgeon gave me certain options, I was so rattled and in shock that I didn’t know what to do or what decision to make, I felt there was not enough time to consider different options.”*

This reactions are in holding with research findings that the diagnosis of a life-threatening illness such as breast cancer can be overwhelming and shocking to patients and their families with a high probability of experiencing distress right after the diagnosis (Brem & Kumar, 2011; Dolbeault et al., 2009; Henselmans et al., 2010; Lim et al., 2011; Spiegel & Rodrigues, 2008).

Even in early investigations it was felt that because a cancer patient might feel overwhelmed at the beginning of the cancer road, a skilled psychologist can facilitate decision making and also act as a liaison between the patient and her physician (Haber et al., 1995). All five patients shared the experience of feeling overwhelmed after they heard the diagnosis of their cancer.

Both *patients I and V* who had young children (between two and sixteen) immediately thought about dying after hearing their diagnosis.

*Patient I* said “the first thing that was going through my mind was that I am going to die and who will be there for my children. From the beginning of my diagnosis, my two children were my biggest concern.”

*Patient V* said that she decided immediately after her diagnosis that she will have to be the strong one for her husband and child and that she will have to take control over all the decision making regarding her cancer.

There are strong evidence in the literature that having young, dependent children under the age of 18, still living at home, increases stress levels and anxiety in breast cancer patients and contribute to fear of recurrence and dying, leaving their young children behind. The confrontation with a person’s own mortality can also cause acute psychological stress (Brem & Kumar, 2011; Dolbeault et al., 2009; Lim et al., 2011; Spiegel & Rodrigues, 2008).

### **7.3.1.2 INTERACTION AND RELATIONSHIP WITH THE ONCOLOGIST AND MEDICAL TEAM**

#### **Theme 2: Inter-relationships with oncologist and medical team: Communication and receiving information regarding the cancer and cancer treatment:**

A number of studies have strengthened the evidence that interaction and communication between patients and their medical teams are especially important in cases of life threatening diseases such as cancer (Barth & Lannen, 2011; Ong et al., 1995; Pollak et al., 2007). Essential and adequate communication between the oncologist and cancer patient is not just about diagnostic information, prognosis and treatment options, but also about mental state of mind, for the lack of this type of communication can cause emotional distress (Barth & Lannen, 2011; Fallowfield & Jenkins, 2015).

All five patients agreed that they had limited knowledge and understanding of cancer treatment before being diagnosed with breast cancer and before they started their treatments. Most of the cancer related information was presented to them verbally by their oncologists and oncology teams and in some cases some have also received information in written format, as in brochures. The five patients consented that the bulk of the information regarding their treatment was mostly

biologically orientated and very little was said about emotional and psychological issues and challenges.

*Patient II* said that even during her third chemo treatment she still didn't know what stage cancer she was in and said:

*"I feel that there isn't very good communication between me and my doctor and because of that I don't have the confidence to talk to him about anything or ask him any questions, even in terms of the reactions of my body to the chemo."* She said that she felt that her doctor was always in a hurry when they were in consultation and did not interact well with her. She stated further:

*"This is a problem for me and makes me anxious not to be able to talk to the doctor. I feel disappointed in the doctor and personnel for not informing and preparing me for my second type of chemotherapy. It made me feel that they do not look out for me as their patient."*

She perceived the lack of information regarding the second type of chemotherapy as a "setback" for her in terms of her emotions and adaptation to the treatment.

*Patient III* stated:

*"That anything you want to know from the doctor, you must ask them specifically, they do not explain anything without you asking."* When asked if she felt comfortable talking to her oncologist about her emotions and sexual fears she said: *"no, we don't speak, the sessions are too short and over very quickly. There is no relationship between me and my doctor"*.

She said that the information she had about the cancer treatment she got from their group session the first day where the oncologist explained some things about breast cancer and the treatment. She said the chemotherapy sisters had also explained what was going to happen during the chemotherapy, saying it made her feel more worthy as a person if it seemed that people tried to help her and be nice to her.

*Patients I, IV and V* experienced good relationships with their oncologists with relatively good communication, but all three felt that although the communication

and information were relevant it was more biological and technically orientated. It lacked the emotional component and impact it would have on them and their families.

*Patient I* reported that although she was being kept well informed about her condition and treatment in the biological sense, she did not fully comprehend the emotional and psychological repercussions of the cancer treatment, or thereafter, both on her and her family. When asked if she felt comfortable speaking to her oncologist about her emotions and possible sexual fears, she said:

*“No, I did not have the confidence to speak to my doctor about my personal feelings or my sexuality, although we had a good relationship it was not on a personal level. It was more medical than emotional.”*

*Patient IV* confirmed that she and her oncologist had a very good relationship from the beginning with very open communication, but also said:

*“While I was academically well prepared and well informed about the cancer treatment, especially the chemotherapy and its side-effects, the emotional impact was still a huge shock on my system. I was not prepared for it.”*

She explained that because of her history with depression and previous therapeutic sessions, she understood the importance of seeing a psychologist throughout the cancer treatment. She understood the role of a psychologist in helping a person with psychological problems and didn't expect the oncologist to help with her emotional state.

*Patient V* also had a good relationship with her oncologist with good open channels of communication. The relationship was such that she felt emotionally supported by her oncologist, hence her request to see a psychologist to discuss her emotional distress. Her oncologist was very positive about referring her and underlined the benefits of psychotherapy to her.

Ong and colleagues (1995) have emphasised that from the patient's standpoint, two important needs have to be met during interaction between them and their doctors, namely the need to know and understand what is wrong with them and

the need to feel known and understood by their doctors. Some researchers found that breast cancer patients typically disclose only half of their emotional concerns to their oncologists and that failure to detect psychological distress is largely due to lack of communication between healthcare professionals and patients (Gandubert et al., 2009; Pollak et al., 2007).

- **Suggestions from the oncologist/surgeon to consult with a psychologist:**

Out of the five patients only one oncologist has asked the patient during the course of her treatment whether she wanted to see a psychologist to help with her emotional problems and two oncologists had referred their patients to a social worker for a standard and compulsory interview without regard of their emotional status or specific needs, or without any feedback afterwards.

*Patient II* who started out as a private patient (and then because of financial matters had to change to the state hospital) said that when she was so anxious in the beginning just after her diagnosis, she was referred by her oncologist to a social worker which was part of the oncology team, saying:

*“I cannot say that the session had helped me in any way in terms of my emotional wellbeing, for the ‘interview’ was more in a technical manner of what to expect from the practical side of the treatment, which helped me a lot, but I didn’t experience it as a treatment or help for my anxiety and fears”.* She said that apart from participating in this study, seeing a psychologist was never mentioned during her treatment regime as a state patient.

*Patient III* said that she never knew what a psychologist does and because of the “stigma” she believed was attached to something like depression, she would never have spoken to or asked to speak to anybody about her feelings.

*“I never knew that a person could see a psychologist if you have cancer and nobody mentioned it during my treatment except when you told us about your study.”*

*Patient I* said: “Not at any given stage during my treatment has the surgeon or oncologist suggested that I see a psychologist, although I was very depressed and anxious. I was referred to a social worker in the beginning of the treatment just after the diagnosis which I understood is mandatory in the oncology practise. I did not understand why I was referred to a social worker, it was never explained to me and psychologically I have not benefitted anything from our one session. I was never again asked if I need to see the social worker again or somebody to help me with my emotional needs.”

*Patient IV* said:

“Yes, my oncologist had asked me whether I would like to see a psychologist, but because of my financial situation I could not afford to see one and had to decline, although I wanted to be treated by a psychologist.” She said that being part of this study made her feel excited, partly because she could help somebody else going through this trauma, but also because she knew she could benefit from the sessions.

*Patient V* asked her oncologist to be referred to a psychologist because she said she realised that she needed to talk to a psychologist about her emotions regarding her cancer experience and also about her husband and child. She said:

“I know what a psychologist does and I realise that I desperately need to see one in therapy.” This request from the patient was only after she was finished with her treatment and in remission and went for a check-up session to the oncologist, explaining to the oncologist that she needed to be referred. Her oncologist was very positive about referring her to the researcher and had encouraged her to make an appointment.

Although recent literature found that a multidisciplinary team approach are becoming more and more central to comprehensive cancer rehabilitation in helping cancer patients to meet their needs, some medical practitioners still find it a challenge to involve mental health services when treating a biological disease (Jalil, Lamb, Russ, Sevdalis, & Green, 2012; Taplin et al., 2015; Turner, 2015). It is believed that medical doctors often do not have the proper knowledge regarding breast cancer and the development of mood disorders and are therefore not

referring their patients when they need psychological help (Gandubert et al., 2009; Vetere, 2007).

### **7.3.1.3 BREAST CANCER TREATMENT: CHEMOTHERAPY, SURGERY AND RADIATION**

There are two themes related to the effects of the cancer treatment on breast cancer patients, namely the biological- and the psychological side-effects.

#### **Theme 3: The impact of the biological side-effects of the cancer treatment:**

- **Chemotherapy:**

According to literature, the most common and unpleasant physical complications of chemotherapy include nausea and vomiting, fatigue, lymphedema, alopecia, cognitive impairment, pain, weight gain and menopause and sexual dysfunctions (which will be discussed in Theme 7), (Brem & Kumar, 2011; Fallowfield & Jenkins, 2015; van Oers & Schlebush, 2013; Weis et al., 2009). The biological side-effects of chemotherapy that were experienced most and in the most severe degree were described by the five patients as follow:

- **Fatigue:**

The most prominent and severe side-effect that all five patients experienced and which affected their quality of life and relationships was that of fatigue, which according to literature, impairs activities of daily living (Dean, 2008; Fallowfield & Jenkins, 2015; Johns et al., 2015; Vahdaninia, 2010). In all five cases fatigue started from the very beginning of chemotherapy up to the present where all of them were finished or near the end of their treatment. They complained about the severity of the tiredness and its persistence and continuity throughout their whole treatment trajectory and thereafter. They all felt that tiredness, although a biological side-effect, had not just influenced their level of functioning but had drastically affected their emotional wellbeing and had also altered their personalities, which left them vulnerable and exposed.

*Patient II* said the tiredness started immediately after the first chemo and affected her emotional health the most:



*“It changed me as a person. Working in and around the house and garden and being active all the time with family activities is what defines me as a person and makes me feel useful and worthy.”* She felt that changing to a more inactive person because of her lack of energy, was a challenge for her.

*Patient III* explained her fatigue as the worst of her side-effects as to date, starting the same day as the chemo.

*“I am so tired during the day that I fall asleep and then sleeps badly at night and then I start to think about bad things over and over and start the day tired”.* She said that even now, after the chemo, she still felt tired with less energy as before the cancer.

*Patient I* said: *“I had to change my ‘being’, for I am a ‘doer’ and an active person with a challenging job and busy household to a more passive life style during the time of my chemo.”*

She experienced that the fatigue had interfered with her activities with her husband and children, but also with her work functioning and the cortisone treatment brought on insomnia which had made the tiredness even worse.

Dimeo and colleagues (2008) confirmed that fatigue and tiredness are frequently related with sleep disturbances, e.g. hypersomnia or insomnia.

*Patient IV* said that her tiredness was there from the start of the chemo, all the time and it contributed to her negative feelings during the duration of the chemotherapy.

*“The tiredness had made me depended on other people, which made me feel vulnerable needing the assistance of other people.”*

She said it was very important for her to feel independent and to do things for herself. She described herself as somebody who had very high expectations of herself and therefore pushed herself very hard to perform at top level. Whether it was at home, or social relationships or at work, saying:

*“The chemo made me feel very listless and lethargic which was very a-typical of how I usually perform. Even now I feel tired all the time and have very little energy to do anything else.”*

Apart from an acute symptom, fatigue can be a chronic symptom, which can incapacitate the quality of life of the breast cancer patient long after the end of chemotherapy (Brem & Kumar, 2011; Fallowfield & Jenkins, 2015).

*Patient V expressed her constant tiredness during the chemo:*

*“As something that kept me from doing ‘normal’ day to day things with my son and husband, making me feel that I was missing out on them”, explaining that even now “Keeping up with my child’s activities can make me very tired.”*

This experience of fatigue by the five participants was in line with research findings which states that fatigue is a common medical complaint and one of the most common symptoms in breast cancer survivors and that the restrictions of cancer-related fatigue on quality of life exists across the whole cancer trajectory and has been characterized as overwhelming and persistent and has to be accommodated by the health care team (Berger et al., 2015; Fallowfield & Jenkins, 2015; Johns et al., 2015).

– **Incapacity of short term memory/chemo fog:**

There is growing evidence that the neurotoxicity of chemotherapy contributes to cognitive changes in the cancer patient which are responsible for visual and verbal memory problems, the inability to pay attention and concentrate and the lack of multitasking. Typical terminology concerning chemo-related cognitive changes are chemo fog and chemo brain, reflecting on mild to moderate symptoms of cognitive dysfunction (Brem & Kumar, 2011; Brezden et al., 2000; Fallowfield, 2015; Fallowfield, 2015; O’Farrell et al., 2013; Raffa, 2010; Shilling et al., 2006). As with fatigue, short term memory problems can continue well into survivorship which fits in with the theory of the chronicity of some of the side-effects of breast cancer treatment (Brem & Kumar, 2011; Fallowfield & Jenkins, 2015).

The three patients, finished with their treatments, experienced loss of short term memory in a prominent way, and because all three of them are in full-time careers,

they experienced the lack of concentration and memory as problematic and incapacitating and threatening to their work functioning.

*Patient I* stated that she had a problem with the fact that she could not remember as well as before, saying:

*“I am not used to be so forgetful all the time and am confronted now for the first time with a dysfunction influencing a lot of my activities, including my work.”*

*Patient IV* said:

*“I experienced chemo-fog in the worst degree which made me feel stupid and slow and not intelligent at all. This was during the time of the chemo and even now, three months after the last chemo, I still feel slow.”* Also saying:

*“Because I am very career orientated and driven, my work plays a large and important part in my life and identity and the prominent lack of concentration and memory threatened my ability to function at my usual level.”*

She said her work entails a lot of concentration and focusing and that she was constantly scared of not being able to do her work properly.

This was underlined by a number of studies, emphasising that memory and attention problems after chemotherapy are recurrently reported by breast cancer patients (Shilling et al., 2005; Shilling et al., 2006; Wefel et al., 2004).

*Patient V* said that although most of her side-effects were gone (it was already 16 months after her last chemo) her short term memory was still bad and that it was causing serious problems for her in her marriage and work. She said she kept on forgetting to do things that her husband asked of her and she displaces things all the time.

*“My husband complains about me not listening to him, but doesn’t understand that I do listen. I just cannot remember it afterwards. The lack of short term memory also affects my work, I work with figures and have a responsible job and I am scared that I will make mistakes and risk losing my job.”*

– **Nausea and vomiting:**



Although the development of antiemetics (anti-nausea medication) have improved drastically over recent years, there is still a percentage of cancer patients that suffer from mild to severe nausea and vomiting and which still remains one of the most dreaded and aversive side-effect of chemotherapy (Antonarakis & Hain, 2003; Fallowfield & Jenkins, 2015; Fernandez-Ortega et al., 2012). Chemotherapy-induced nausea and/or vomiting can severely impair a patients' quality of life, therefore the awareness of health care providers is important for proper diagnosis and management of this complications (Fernandez-Ortega et al., 2012; Hilarius et al., 2012).

*Patient II* experienced nausea from day three for a couple of days in spite of the anti-nausea medication, but mentioned that she had never vomited from the chemotherapy, saying that this is not a 'big' side-effect for her.

*Patient III* and *Patient IV* have never experienced or complained about nausea or vomiting while *Patient I* had experienced nausea, but not vomiting, together with aches and pains in her body and a metal taste in her mouth for at least seven days after each chemotherapy session. This is explained in recent literature claiming that chemotherapy-induced vomiting can be prevented in nearly 70% to 80% of the patients with effective antiemetics, but that the management of nausea is more limited with only a success rate between 31% and 45% despite the administration of optimal antiemetic prophylaxis (Fernandez-Ortega et al., 2012; Hesketh, 2008).

*Patient V* experienced the worst case of nausea and vomiting of all five patients saying she experienced severe biological side-effects from the chemotherapy that started the very first day with the "Red Devil". She further stated that she was completely unprepared for the side-effects, especially the nausea and the vomiting which started a couple of hours after the administration of the chemo. She experienced vomiting the most overwhelming of all the side-effects of the chemotherapy. It had made her physically ill and kept her from participating in any activities with her husband and child. It was so bad, she said:

*“I was so surprised. I understood from other patients that nausea and vomiting are not so big anymore because of the anti-nausea medication, but I had experienced it extremely viciously. The vomiting kept on for days after the chemo, no medication worked for me, the vomiting was worse at night and I didn’t want my husband and child to see me like that.”* She said that this was also the time when she was most scared of dying and was very anxious.

This type of nausea is called acute nausea and begins within minutes of chemotherapy administration (Antonarakis & Hain, 2004; Ryan et al., 2012) and literature underwrite her emotional experience by declaring nausea as a “toxicity” that has a negative effect on the daily life of the cancer patient (Fernandez-Ortega et al., 2012).

– **Alopecia:**

Although all five patients lost all their body hair, three of them were severely affected and shaken from their hair loss and described it as follows:

*Patient II* experienced hair loss directly after the very first “Red Devil” chemo saying:

*“I was okay with it because it was explained to me by the oncology sister and was prepared for it to happen. It did not affect my self-image the way I thought it would and I was never ashamed of my hair falling out or even to walk around bare headed.”*

She said she had prepared herself by buying a wig and some headbands in advance, but because her husband and family were so supportive and positive concerning her hair loss, she could cope better with the situation.

*Patient III* said although she knew about her hair that was going to fall out, she was still shocked and unprepared when it happened, saying:

*“With my hair falling out the reality of the breast cancer hit me for the first time. I freaked out when I saw my hair falling out in lumps. It was very traumatic for me and I feel quite self-conscious and don’t feel like going out in the public even when my head is covered. The situation with my hair even caused conflict between me*

*and my husband, because he felt I should have prepared myself better for this and I should not have allowed it to upset me so much.”*

*Patient I* said the total hair loss of her whole body and the changed shape of her breast was the worst part of the changes in her body:

*“It affected my body image which was already compromised by the surgery and the changed shape of my breast”.*

*Patient IV:* *“The falling out of my body hair was quite a weird experience for me, especially together with the weight that I gained. It influenced my self-image quite a lot.”*

*Patient V* said, when asked about her hair:

*“The loss of my hair was a shock, but I was more worried about the reactions of my husband and child. My husband took it very hard and would not allow me to go out without a wig or head band, I felt he was ashamed about my cancer and me without my hair”.*

She said because of her child’s very young age, she made him part of the process of shaving her hair so that it was not a shock for him seeing her without hair.

The negative perceptions regarding alopecia and appearance was supported by literature stating that alopecia ranks amongst the first three most feared and traumatizing side-effects of cancer treatment and can be extremely distressing (Kim et al., 2012; Lemieux et al., 2008; Van den Hurk et al., 2010). Alopecia can affect a person’s self-image and sexuality and can incapacitate her social activities and relationships, with some patient’s even reporting feelings of shame because of their hair loss (Kim et al., 2012; Lemieux, 2008).

– **Pain:**

*Patients II and III* were severely affected by pain due to their second type of chemo, Taxol, which they got during the time of our sessions, saying that they did

not anticipate the severity of their pain because they did not experience any pain with their first chemo ("Red Devil"). Taxol is a common anti-cancer drug that induces neuropathic pain by an unknown mechanism (Gutiérrez-Gutiérrez et al., 2010; Warwick, & Hanani, 2013).

*Patient II* said "All of a sudden I experienced vast amounts of pain in my whole body especially in my fingertips and feet and this interfered with my sleep and even made me vomit once. This was very bad and scary for me. I didn't see it coming and I was not prepared for it".

The pain worsened her tiredness which was already bad. She said the pain medication was only helping to a certain extent. She also developed sores in her mouth, had a bad cough and tight chest and her nails had turned blue. This was all due to the new chemotherapy which she felt was not explained to her properly and because she was not prepared she said the emotional effect was so much worse.

*Patient III* said with the new chemo (Taxol):

*"Pain was a new side-effect which I did not know would happen and nobody had told me about the new and different side-effects of the chemotherapy. The pain was now the worst side-effect that I had up till now, with the most pain in my fingertips and soles of my feet, I had numbness underneath my feet and my whole body was sore"*.

She also said her appetite went down but she forced herself to eat properly, she had heartburn and sores in her mouth and her nails had turned blue. She experienced that the pain had worsened her emotional status, and especially her feelings of anxiety and fear.

*Patient V* experienced pain in her arm where they inserted the needle for the chemo which was very painful especially at night. She found herself waking up because of the pain. Apart from that, pain did not play a big part in her cancer treatment regime.

Studies supported the notion that pain can be a common symptom found in breast cancer patients and that approximately 20% to 40% of cancer patients who receive neurotoxic chemotherapy will develop painful peripheral neuropathy (Lueboonthavatchai, 2007; Vahdaninia et al., 2010; Smith et al., 2013; Sohl *et al.*, 2014). *Patients I and IV* fell in the category where pain were not a factor, although they both experienced pain during their surgery, it did not make a noteworthy impact on them psychologically.

- **Surgery:**

Three of the five patients had lumpectomies, one patient had a radical mastectomy of the right breast and one patient had a double mastectomy and complete hysterectomy. All the patients had axillary lymph node removals as part of their surgical procedure. Although pain is mentioned as one of the main side-effects of the various cancer treatments and a biological factor regarding surgery, (Brem & Kumar, 2011; Ganz et al., 2004; Golden-Kreutz et al., 2005; Lueboonthavatchai, 2007; Vahdaninia, 2010), the five patients in this study did not overtly complain about severe pain at their surgical sites. Three of the patients developed lymphedema as side-effect of the surgery and consequently experienced pain and swelling and discomfort in their arms and shoulders. This is in line with findings claiming that some breast cancer patients report worse results after the axillary surgery in terms of pain and discomfort than the surgery of the breast self (Brem & Kumar, 2011; Fallowfield & Jenkins, 2015).

The one on-going theme in terms of surgery was that of acute fear and anticipation anxiety before the surgery which was very dominant with the two patients (*Patients II and III*) who was waiting for their surgery during this study, so much so that *Patient III* had asked to carry on with therapeutic sessions asking:

*“Can I continue seeing you before and after the operation, I am too scared to do it on my own”.*

*Patient II and III* both experienced lymphedema and *Patient II* said that although she handled the healing process well both in terms of the operation and emotions:



*“The worst pain that I had from the beginning was in my arm and not the surgical scar, I still experience pain in my arm and go to a physiotherapist for sessions and use the exercises that the physio had taught me”.*

Patients I and IV didn't experience any pain in their arms or shoulders and didn't even feel that pain was a factor where it concerned their surgery, while *Patient I* said that she felt that she handled the operation physically and emotionally better as when she heard she had breast cancer.

*Patient V* said the practical side of being away from her family for long periods of time because of the surgery outscored any physical side-effects. She had a double mastectomy and reconstruction of both breasts at the same time, and yet the physical side was never a problem for her. She had good pain medication and she felt she did well physically. She said that after the complete hysterectomy she only experienced mild pain and discomfort.

Only two of the five patients (Patients I and V) had breast reconstruction surgery. They both decided on the procedures because of their younger ages and their need to regain some of their body image back and rebuilt their sexual self-esteem. Both said that they did not even consider not undergoing breast reconstruction. This was in keeping with research findings that women who had undergone breast reconstruction after mastectomy were younger in comparison to those who had no reconstruction (Albornoz et al., 2013; Anagnostopoulos & Myrghianni, 2009; Fallbjörk et al., 2010). The two patients who were still busy with their treatment did not see breast reconstruction as an option for a better self-image at that stage. Patient IV said that although she had not considered breast reconstruction up till the current time, she was seriously considering breast reconstruction now because of her deformed breast and low self- and body-image. Albornoz and colleagues (2013) confirm that breast reconstruction can have benefits in body image, self-esteem, sexuality and quality of life.

- **Radiation therapy:**

Some of the most common side effects of radiation are fatigue and the damaging of healthy cells and tissues near the treatment area such as reddening of the skin, discomfort and swelling of the breast and tiredness (Berger et al., 2015; Haber et al., 1995; Johns, 2015). All five patients underwent radiation therapy after their surgery and chemotherapy but it was only *Patient I* and *Patient IV* who experienced outspoken physical side-effects of radiation therapy, with *Patient I* saying:

*“I again experienced fatigue and pain as well as sensitivity in the breast area where they applied the radiation therapy. It was much easier in a way than chemotherapy, both in a biological and emotional way. It was just the inconvenience of having to travel every day to and from the oncology rooms.”*

*Patient III* said the only symptom that she experienced from the radiation was light headedness while *Patient IV* confirmed that the radiation “*was not bad at all, it was more of a practical issue, the effort to go in to the oncology rooms every day*”. She said her skin was a little bit red but had healed quickly again.

#### **Theme 4: The impact of the psychological side-effects of the breast cancer treatment:**

Recent studies have demonstrated that breast cancer patients especially, are inclined to be psychologically fragile because of the stress of the diagnosis and the draining of long treatments, pain, unpredictability of the course of the treatment and the chronicity of the disease. It further suggests that at least one in three breast cancer patients will experience noteworthy psychological distress at some stage during the course of their illness. These psycho-socially harmful side-effects can manifest at the time of diagnosis and persevere throughout survivorship (Borras et al., 2014; Brem & Kumar, 2011; Fallowfield & Jenkins, 2015; Lueboonthavatchai, 2007; Mello et al., 2013; Spiegel, 2008), and was well documented during the sessions with the patients in this study.

- **Chemotherapy and emotions:**

In this study the prevalence of psychological symptoms was found to be higher in breast cancer patients undergoing chemotherapy than when receiving

radiotherapy. This can be attributed to the severe negative effects of the chemotherapy agents, post-treatment uncertainty and the occurrence of psychosocial problems (Roa et al., 2009; Saniah & Zainal, 2010; So et al., 2009). Depression, together with fatigue and disrupted sleep are some of the most common side effects of chemotherapy for cancer and often co-occur with and are significantly associated with negative mood (Jim et al., 2011; Badr et al., 2006; Palesh et al., 2010). Studies that explored longitudinal changes in various symptoms during chemotherapy have reported a “roller coaster” effect, meaning that the symptoms are highest in the week following a chemotherapy infusion, and then decline prior to the next infusion, just to start all over again (Jim et al., 2011; Badr et al., 2006; Palesh et al., 2010). The psychological side-effects of chemotherapy are some of the themes that were the most prominent and vividly experienced and described by all 5 breast cancer participants. This was the case with the patients still busy with their treatment and the three who had been finished for quite a while and was in remission.

*Patient II* explained her breast cancer as a busy illness, saying:

*“The travel to and from the hospital and waiting for either procedures or results kept me very busy and occupied. Me and my family are physically and emotionally tired from my cancer and really need a vacation now away from the hospital and cancer experience.”* She explained that the tiredness due to the chemotherapy affected her emotional health and her mind the most.

*Patient III* said that the day that she found out about her cancer and the day of her first chemotherapy were the worst for her. Saying she felt extremely scared of the chemotherapy and didn't know how to handle or prepare for it.

*Patient I* described her chemotherapy as:

*“It was a very busy and demanding time of traveling and sitting in the chemo room not being able to do anything else. Even the days after the chemo I felt unavailable for my children and husband, especially on the days that I felt so tired and hopeless. The tiredness played a big part in my emotional status and depression”.*

*Patient IV* said that she had a lot of bad biological and emotional side-effects from the chemotherapy, calling it “*emotional turmoil*” and saying:

*“The chemo was relentless, especially when I had to get chemo every week for nine weeks”.*

She said that for the entire duration of the chemotherapy she was feeling negative and depressed. Saying that she experienced cancer to be an extremely busy illness, especially the chemotherapy:

*“You don’t know how to juggle everything with the treatment and the work and relationships. It put a lot of stress on me”.*

*Patient V* said the chemotherapy (which had already stopped 6 months before):

*“Feels literally like yesterday. The pictures in my head of the chemo room are still very vivid and bad, and I can still see the red colour of the chemo and smell and taste it.”*

Here she experienced some symptoms of a Post-Traumatic Stress Disorder, that is also typical of a breast cancer experience (Berger et al., & Kumar, 2011; Dolbeault et al., 2009; Holcombe et al., 2010; Nekolaichuk et al., 2011; Reyes-Gibby et al., 2012). She said she experienced the chemotherapy as traumatic and scary and it completely overwhelmed her. During the period when she received chemotherapy she felt vulnerable and emotional and was crying a lot, not understanding all her emotions, saying:

*“Especially at night when I couldn’t sleep, I felt alone and scared and constantly thinking of death and dying, leaving my son behind. When I was so ill and nauseas and throwing up the whole time I honestly wasn’t sure if I would make it and wondered if this is what dying felt like”.*

- **Feelings of depression and the diagnosis of depression throughout the trajectory of cancer treatment:**

The breast cancer patient has a strong probability, according to literature, to develop depression or symptoms of depression during the course of their

treatment (Burgess et al., 2005; Fan et al., 2008; Meier, 2010; Reyes-Gibby et al., 2012). Because of this high incidence, Burgess and colleagues (2005) underlined the need for devoted psychological service provision during this time. This occurrence was supported by this study where Patients I, III and IV developed outspoken symptoms of depression after the first 12 months of diagnosis (although not diagnosed or treated in the case of Patient IV) while Patient V fitted more in with studies stating that a substantial number of breast cancer patients report a late increase in distress and psychological suffering in the re-entry and remission phase (American Cancer Society, 2010; Burgess et al., 2005; Henselmans et al., 2010).

*Patient II* felt, in the beginning of her treatment, that the cancer was more of a challenge for her thought processes and psyche than anything else and didn't want to become negative and made a point of staying focussed on positive thoughts. As the treatment went on and the tiredness became worse, she experienced much more negative emotions. After starting with her new chemo, (our fourth therapeutic session), she experienced emotional distress for the first time due to the lack of information regarding the side-effects and consequently could not prepare herself properly for the onslaught of the symptoms. She said:

*“Because I didn't know or expected any of the new side-effects it was such a shock. I was very anxious and scared not knowing what was happening to my body.”*

She never developed symptoms of depression during her treatment trajectory, although she felt down and tearful and emotional because of the tiredness during the chemotherapy and not knowing how to deal with it. She said that she could relate to the fact that her mood changes were connected to and because of the chemotherapy, saying:

*“I am not usually a depressed kind of person”.*

When she filled in the HADS, she scored a 4 on the depression side, which fell into the normal scoring of 0 – 7 and fitted in with her mood at the beginning of her treatment.



*Patient III* experienced the cancer and cancer treatment from the beginning as emotional, and was very tearful for most of the time during the sessions. During the second consultation while busy with chemotherapy, she said:

*“I am crying a lot more lately and feel very emotional”.*

When asked about feeling depressed, she said she had always connected depression with shame, saying:

*“Knowing that there is a stigma when you feel depressed, I find it difficult to speak about my emotions or admit that I feel depressed to anyone.”*

During our last therapeutic session, after her surgery and while she was still busy with her radiation therapy, she seemed very depressed. More so than the previous sessions and it was decided that she would be assessed according to the DSM-5 criteria to see whether she presented with the hypothalamic symptoms of depression. She met all the criteria for a major depressive episode and an antidepressant was prescribed on the researcher’s request by the oncologist.

Her score on the HADS, which she filled in, in the beginning of the therapeutic process, was a 6 on the depression side, which fell into the normal range between 0 and 7). There was a clear change from only feelings of depression in the beginning of the treatment regime, to the end where she presented with a full scale major depression due to the cancer and cancer treatment.

Literature underlines that there is still prejudice about mental illness and psychological problems even in the context of a medical illness such as cancer (Holland, 2004; Kalaitzi et al., 2007). This kept patients from admitting to psychiatric symptoms and getting treatment. It was also evident with these patients that experiencing an episode of depression or anxiety soon after the diagnosis of, or during treatment of breast cancer, can add to the pain and suffering of the patients and the burden on their family (Meier, 2010).

*Patient I* said that she felt severely down and depressed at the time of her treatment;

*“I was scared that I would not be able to go back to normal or to what normal was for me before the cancer, but to me the anxiety was even worse than the depression because you can feel the anxiousness in your body the whole time”.*

She felt that the cancer treatment was actually taking her away from her normal life and normal activities and she was concerned about the time away from her home and family. She said that she felt most emotional when she was just diagnosed, just before the surgery and before her first chemo;

*“Not knowing what to expect at all made me very emotional and scared. I have developed both depression and anxiety and although I am working in the medical field I did not realise it at that moment and my oncology team did not, at any given time, discuss the conditions with me or acknowledged it. I was never given the option of seeing a psychologist”.*

Patient I’s depression score on the HADS, which she filled in in the beginning of the study, (between the first and second session) was a 7 which was in the normal range. It reflected her current state, which was not as depressed as she was during and just after the treatment. She was, at the time of this study, on an anti-depressant.

Both *Patient I and IV* were diagnosed with and treated for depression before their cancer diagnosis by their treating psychiatrists. Neither of their conditions was accommodated during their cancer treatment, which underline a study done by Jacobson and Jim (2008), claiming that the need for psychological care is mostly under-recognised by the primary oncology team therefore goes unnoticed and undertreated.

*Patient IV* said:

*“I noticed that while undergoing the cancer treatment that, especially with the chemotherapy, my symptoms of depression increased. I was more scared of becoming depressed again because of the cancer diagnosis and treatment than I was for the cancer itself!”*

Because of her history of depression she realised that she could become depressed again and immediately contacted her psychiatrist to ensure that her psychiatric medication (which she was still on) would be effective with the extra stress of the cancer treatment. She said:

*“I realised I would need to see a psychologist, but could not afford to see one. I could literally feel how the depression worsened every day. It was the severest form of depression I ever had and for the whole four months of my chemotherapy I felt physically ill and emotionally upset.”*

She said her sleeping pattern had changed immediately from day one and she suffered from insomnia, saying that she was not sure if it was because of her mood and depression or if it was the chemo. Her score on the HADS which she filled in, in the beginning of our sessions was 13 which was in the abnormal category and was a true reflection of her mood status when we started with the sessions. Although she presented with symptoms of depression from the beginning of our sessions, which was also the reason why she was referred, she was already on an anti-depressant and under treatment of a psychiatrist. Her therapeutic sessions continued, but by the fourth therapeutic session (five months after her last treatment) there was a need to assess her symptoms again for depression (according to the DSM-5 criteria) because her mood was spiralling down and she became much worse. There was concern about her psychological condition. She was referred back to her psychiatrist to look at her medication and maybe to make adjustments to meet her current needs. Hill and colleagues (2010) confirmed that a pre-morbid psychiatric history is a well-known risk factor in developing depression during and after breast cancer and cancer treatment, especially in the year after diagnosis. It was also further confirmed that there are overlapping somatic symptoms between depression, chemotherapy, radiation and hormonal therapy which can make the diagnosis, and treating of depression, difficult (Lueboonthavatchai, 2007).

*Patient V* said she was feeling depressed (15 months after the diagnosis and 6 months after the last treatment) about her losses and because of her marital problems and that was why she had asked her oncologist to see a psychologist. She was evaluated by the researcher in terms of her symptoms and was found



presenting with all the DSM-5 symptoms of a Major Depression. It was explained to her that treatment for depression can include both medication and psychotherapy, and she had opted for the therapy first before going the route of an anti-depressant. The patient explained that she never experienced depression or anxiety before the cancer or had any treatment for such conditions,

*“But now I am very worried and troubled by my emotions and the relationship with my husband, because I thought that I would automatically feel better once I was finished with the treatment, but it is not the case”.*

In spite of her clinical diagnosis of depression, her score on the HADS on the depression side was only 6, not corresponding with her true symptoms and feelings of depression. It is important to note here, that if she was only subjected to a questionnaire for measuring depression, she and treating doctor would have gotten the wrong impression that there was no sign of depression. Symptoms of depression or emotional distress can cause a contradictory response for survivors who may feel both relieved at having completed treatment, but also a heightened anxiety for recurrence (Ganz et al., 2004; Saniah & Zainal, 2010).

- **Anxiety and anticipation anxiety during the cause of breast cancer**

There is strong evidence that shows that anxiety is a prominent concern regarding the three main treatment modalities of breast cancer namely surgery, chemotherapy and radiotherapy (Dolbeault et al., 2009; Lim et al., 2011; Lueboonthavatchai, 2007; Navari et al., 2008; Vahdaninia et al., 2010).

*Patient II* was so stressed out and anxious after hearing the diagnosis that she was referred to a social worker by her oncologist at their first appointment, saying:

*“After the appointment I still felt anxious and I did not know how to handle that at all. I am not an anxious or depressed type of person and didn’t know what to do with all that anxiety and fear.”*

Both *Patients II* and *III* experienced severe anxiety (anticipation anxiety) regarding their upcoming surgery that was scheduled for after their last chemotherapy. They

confirmed that they were more scared before they knew what the surgery would entail. *Patient II* said:

*“I was in denial of the surgery and so busy with the chemotherapy that I was not thinking about the operation at all. Now after hearing the confirmation of the surgery date, it is a reality and I am scared now.”*

She said that the oncologist had commented on her anxiety, but after he explained what the surgery would involve and what she could expect, she felt more at ease about the whole procedure. For the researcher this was another indication of how important communication between the oncologist and/or surgeon and the breast cancer patient is and the peace of mind that goes with knowledge regarding the cancer procedure.

*Patient III* also commented on her fear of the upcoming surgery, saying:

*“I was trying to be positive but felt very emotional and anxious most of the time before the surgery. I felt so scared and apprehensive of the forthcoming surgery that I was not even joyful at the end of my chemo or when I heard the good news that the tumour had remarkably shrunk.”*

Recent literature confirmed the experiences of Patients II and III that the pre-operative stage is dominated by stressors such as waiting for the surgery and the pathology results causing high levels of anxiety (Aviado-Langer, 2014; Berger et al., 2015). Both Patients II and III tested within the normal range of anxiety on the HADS, which was not a completely true reflection of how they felt in terms of anxiety. They were both anxious enough to have complained about it and for me to feel that it must be addressed in therapy.

*Patient I* explained that, to her, the anxiousness was worse than the depression:

*“It was like a physical presence, especially the anxious thoughts of the cancer that didn’t seem to go away. It was as if the anxious thoughts were just milling around in my head the whole time”.*

She said that, during her stay in the hospital before the surgery, she was very anxious but not depressed:

*“The waiting in between the procedures and the results was hard-core anxiety. After the end of the treatment, when I thought I would be glad and happy, the anxiety was back again because I was unsure of what the future held for me and if and when the cancer would re-occur.”*

She experienced that her fear and anxiety was even worse after the end of the treatment when everything was supposed to be back to normal, saying:

*“My biggest disappointment was the realisation that this anxiety and fearful thoughts will never end, that there will never be a full stop after the sentence”.*

She was diagnosed with, and treated for a general anxiety disorder by her psychiatrist after her cancer treatment was over and she was in remission. The anti-depressant Cipralex 20 mg was prescribed by her psychiatrist. Before the cancer diagnosis, she had never been treated for an anxiety disorder, although she suffered from a major depressive episode previously. Her score on the anxiety side of the HADS was 6, in line with how she felt when I started seeing her in therapy. She said that although she was still having her anxious moments, it was more under control with the medication and sessions with her psychiatrist.

*Patient IV* said that, from the beginning of the diagnosis, the biopsy and surgery and then the chemo:

*“I was scared and afraid and was anxious because of my fear of needles. The whole process of administering the chemo was very intimidating for me because of my fears.”* Although this patient experienced more feelings of depression, and talked more about her depression, she still tested 13 on the anxiety side of the HADS, indicating that she also suffered from severe anxiety in the beginning of our sessions combined with her feelings of depression.

Most of *Patient V's* fears and anxiety revolved around her child. She was scared of dying and leaving him behind. She was also worried because of the high responsibility of her job, she was anxious about making mistakes or even losing her job. She requested an appointment with a psychologist because she was so depressed and anxious all the time. This patient's anxiety score was 6 on the HADS, indicating that although she experienced symptoms of anxiety to such a

degree that she felt that she needed therapy, it did not reflect on the HADS. This made it very clear for the medical team and the psychologist to ask about anxiety (and depression) and not just rely on tests and tests results, for it might not be a true indication of a patient's real experience of her mood.

Anxiety, according to some authors, should be distinguished from depression because the interventions differ depending on the nature and severity of the symptoms (Burgess et al., 2005; Dunn et al., 2011; Stark et al., 2002).

#### **7.3.1.4 THE EMOTIONAL EXPERIENCE OF THE CANCER JOURNEY DURING AND AFTER TREATMENT: SPECIFIC PROMINENT EMOTIONS**

##### **Theme 5: The need to talk about emotions:**

Breast cancer causes, amongst other things, unpleasant emotional experiences leading to psychological distress (Hack & Degner, 2004; Stanton & Low, 2012), and evidence suggested that by acknowledging, understanding and sharing negative emotions it can give positive relief which can be associated with improved well-being (Austenfeld & Stanton, 2004; Hack & Degner, 2004; Stanford et al., 2000). These authors underline the importance of crying, talking and writing as a healthy outlet of the breast cancer patient's emotions.

*Patient II* said she had tried to make a point of talking about how she felt to her family, especially in terms of her emotions regarding the cancer, but felt a need to speak to a professional person about the cancer process and how she felt about everything. She felt that talking to her oncology team was more about statistics about cancer survival which she was not so interested in. Instead she rather needed somebody to talk to about the treatment and her emotions, saying:

*"I would rather want to know what to expect of my treatment and my emotions, more than what the cancer statistics are, 'over sharing' makes me anxious".* She said because of this (her need to talk) she decided to participate in the study after understanding what it would entail.

*Patient III* had a sincere desire to talk about her emotions, which she experienced as overwhelming, not just regarding her cancer, but also about the worries she

had before the cancer concerning her family life and marriage and her and her husband's chronic illnesses. During the first session she asked:

*"Will it be possible to work on that as well during our sessions because of my problems with my family? I don't have anybody to talk to about how I feel about my cancer. I have always found it difficult to talk about how I feel."*

*Patient IV said: "If I could see a psychologist from the beginning, working through my emotions the whole time, I think I would have been able to control my emotions better".*

She also said *"I need to see somebody to talk to about my deepest feelings and to help me to put everything in perspective. It was because of this need to talk about my emotions and to prevent a relapse of my depression that I wanted to see a psychologist from the beginning ..."*

*Patient V said: "I need to talk about my emotions and the hardship I went through during my breast cancer period even although it is finished. I want to talk to somebody that will understand my situation and can give me some advice as to what to do now, somebody outside my family."*

- **Fear of death**

For most individuals, a cancer diagnosis is often accompanied by fear of death, which makes out a large percentage of the overall fear that the breast cancer patient experience and tend to be the highest in the first few months after diagnosis (Fobair et al., 2006; Waljee et al., 2008; Yoo et al., 2010). Gurm and colleagues found in a study done in 2008 that, regardless of culture, nearly all breast cancer patients experienced that death was impending upon hearing the diagnosis. Four of the five patients in this study experienced high levels of intense fear of dying especially at the beginning of their diagnosis.

*Patient II never pertinently experienced or talked about fear of dying, although she had other fears, especially regarding the surgery.*

*Patient III said: "I thought I was going to die immediately when I heard that I had cancer and I am very scared of dying. Dying was the only thing I could think of."*

A family member of her had died during the time of her chemotherapy due to cancer, which had triggered a lot of fear, especially fear of dying, she said:

*"I have such a need to talk about my fears to somebody."*

*Patient I* experienced that her biggest fear, even after she was in remission, was the fear of death.

*"...not so much for me, but for my children, which are still young...my first thought after hearing the diagnosis of breast cancer was that of dying."*

She explained that she was reluctant to talk about her fear of dying with her family and friends, feeling that by doing so, she would appear to be 'unthankful' of her good prognosis. She had a prominent desire to share her fear of death without feeling guilty for doing so.

Although *Patient IV* was not scared of dying and felt comfortable talking about death, her partner did not like to talk about the subject at all. She felt it is important that when you are in a relationship, to be able to talk about death and dying, especially about the practical matters. During the conversation she asked if we could make an appointment with her partner to talk about this subject later on in therapy. I agreed that it will be a sensible topic to discuss together in therapy.

*Patient V* said that to her, the fear of death was very prominent during her chemotherapy because she was physically sick and really thought that she was dying especially at night, often wondering "... if this was what dying felt like". She said during the three days after chemo when she was so ill with the nausea and vomiting, she constantly thought about death and what will become of her child if she was to die. She said:

*"... even now, I am scared of the cancer coming back and that he, being an only child, will grow up without his mother and other siblings ...I have a lot of sad feelings and anxiousness if I think of him growing up without me."*

- **Guilt Feelings**

Most cancer patients experience feelings of guilt in some form or another. Some may feel that it was somehow their fault (the breast cancer) and that because of them, feelings of pain and distress are imposed on their loved ones and that they are a liability to them (Drageset et al., 2011; Parrish & Adams, 2003). Feelings of guilt are often part of a depressed mood which can be a prominent mood disorder in the breast cancer population (Jim et al., 2009).

*Patient II* stated that she constantly felt, without any reason, that she should prove herself to her husband and family. They should see that she could still do everything in and around the house in spite of the cancer. Not doing her normal house chores, made her feel guilty and not good enough as a mother and wife.

*Patient III* experienced feelings of guilt before her surgery, for leaving her husband alone and not being able to look after him and his needs (he also suffered from a chronic disease). She also had guilt feelings for their financial situation, as she was the main breadwinner and couldn't cope with going back to work during her treatment.

*Patient I* said she often felt guilty when she was feeling depressed or anxious and therefore seldom allowed herself to feel or share these emotions with her family. She felt especially guilty for not being able to participate more in family interactions during her chemotherapy and that she was not part of the 'practical on goings' in her children's lives.

*Patient V* experienced guilt feelings towards her mother and husband and especially her child, as her most prominent emotion, even more so than her fear of death. She felt she had forsaken her child, saying when she was so ill that:

*"...he was missing out on his mother because I was not there to help him with his daily care. ...I was not even able to help him get ready in the mornings for pre-school or taking and fetching him".*

She said she also felt guilty and disappointed in herself for feeling depressed and anxious now after she was in remission, saying:

*“... I am clean and healthy and yet I feel depressed and anxious, it makes me feel even more guilty ...I feel so unthankful and ungrateful.”* She thought that she would feel better and exited after the end of the treatment, but now instead, feeling rather *“...depressed and out of sorts”*.

- **Losses experienced because of the breast cancer**

Cancer can cause multiple losses which include physical and psychological elements and can lead to or even re-stimulate depression and by facilitating the very important grieving process, it is important for the patient to acknowledge and understand what her losses are (Fobair & Spiegel, 2009; Giese-Davis et al., 2010; Lee, 2008).

*Patient II* experienced her biggest losses in terms of her inability to fulfil her “responsibilities” in and around the house as a wife and mother who made her feel useless and unworthy. She felt she lost part of her functionality as a woman and a mother.

*Patient I* experienced it quite a loss to have scaled down on her activities, especially with her husband and children, making her feel “distant” from them, contributing to her feelings of sadness and guilt. She said that the loss of oestrogen and changes in her sexual functioning, as well as the loss of intimacy between her and her husband, was some of her biggest losses throughout her breast cancer and made a huge impression on her emotional wellbeing and overall functioning

*Patient IV* experienced the fact that she was dependant on other people during her cancer treatment, especially the chemotherapy, as a loss of her autonomy, contributing to her depression, saying:

*“My biggest loss was the fact that I could not trust my own body, I felt betrayed by my body and that when you have cancer, you don’t have control over your body anymore or what is happening to it. All of a sudden other people got to make decisions over your body and especially for somebody like me who is extremely private and independent the fact that I was so vulnerable and defenceless was a major loss for me”*.



Another loss for this patient was her financial losses due to the cancer treatment which is very expensive, she said:

*"I never realised how expensive cancer treatment was and I had to use all of my savings to pay for the treatment".* The patient did not at that stage has a medical aid and was still recovering financially from the cancer.

*Patient V* explained that she experienced their changed marital relationship and conflict as a very big and traumatic loss, especially because they had such a good and functional marriage before the cancer, saying about her child:

*"...I have lost out on a lot of new 'developments' during the year I was not so intensely involved in my child's life, I can never get the time back".* She said that it was part of her child's 'baby years'. He was only two then and she had missed out on it, again making her feel intensely guilty and sad.

### **7.3.1.5 Sexual functioning affecting by breast cancer and breast cancer treatment: chemotherapy, surgery and hormonal therapy**

Here the researcher distinguished between two themes (theme 6 and 7) discussing first sexuality and sex reacting to the cancer treatment regime and then menopause and the psychological effect it had on the breast cancer patient.

#### **Theme 6: Sexuality and sex:**

Cancer is regarded as a disease which not only disturbs a person's biology and emotional status, but can also affect and influence her self-image, sexual functioning and sexuality (Surbone et al., 2013; Wong-Kim & Bloom, 2005). Psychological distresses, including psychiatric conditions such as depression can also have a profound effect on sexuality and sexual confidence and lack of sexual desire (Dean, 2008; Graziottin & Leiblum, 2005; Laumann et al., 1999).

#### **Discussing sexual functioning with the oncologist/medical team**

In spite of evidence that many cancer patients would like to discuss sexual issues related to their cancer treatment with their oncologists, recent research has shown that they are reluctant to do so because of limited opportunity and because of their own discomfort to talk about sex and sexuality with their doctor (American Cancer

Society, 2013; Hummel et al., 2015; Kuo et al., 2008; Reece et al., 2010). On the other hand it was found that 62% of the oncology physicians have acknowledged in a study, that conversations about sexual health usually do not occur during the course of the cancer treatment and that they are not at all likely to initiate conversations about sexual dysfunction with their cancer patients (Park et al., 2009). A cancer patient needs an encouraging and confident relationship with her physician(s) to voice her sexual concerns and many patients believe that if a physician does not bring an issue up, then it is not a valid concern worthy of discussion, meaning that if sexual health conversations are not 'physician initiated', then they will most probably not happen (Butler et al., 1998; Hordern & Street, 2007; Park et al., 2009).

*Patient II* spoke spontaneously during the first session to me about their sexual functioning which stayed "normal" and satisfying during the whole treatment regime, but haven't discussed any sexual subject with her oncology team. She said it never came up anyway.

*Patient III*, when asked if she felt comfortable to talk to the oncologist about her emotions and sexual fears or functioning said:

*"...no, we don't speak. ...not even about other side-effects of the chemotherapy."*

Emphasising again that the oncologist doesn't spent enough time with her during their sessions, saying:

*"It helped to speak to you about sex during our sessions and it feels comfortable talking about that".*

*Patient I* explained: *"...that nobody has spoken openly to me about probable changes to my sexuality and sexual functioning. I had to struggle through my sexual problems and challenges on my own, not having the confidence to ask my oncologist about it ... although I was told about the side-effects of the treatments it was never explained to me in detail of what I could expect of my body and emotions or the influence on the quality of my sex life or even what I could do to adapt to the situation, nor was I referred to a psychologist to attend to the problem."*

She emphasised again the lack of communication between her and her oncologist in this field, saying

*“I didn’t feel comfortable discussing my sexual status and accompanying emotional status quo”.*

Dean, (2008), suggested that although sexual problems, due to cancer treatment, may improve over time, some patients might still need additional psychological support following treatment to help them adjust to a better level of functioning.

*Patient, III and IV haven’t* discussed their sexual functioning with their oncologists, but felt comfortable speaking to me in the sessions about their sex lives.

*Patient V* said her oncologist had explained the side-effects of the hormone treatment to her in terms of the menopause, but said:

*“... I feel I need more information about what the treatment will do to my body since menopause is something unfamiliar to me. ...nothing else was said or explained about sex during my treatment.”*

### **Changes in sexual functioning**

All current cancer treatments, especially chemotherapy, cause changes in the female body and although it may not necessarily interfere with the women’s physical ability to have sexual intercourse, it often affects sexual functioning and intimacy and consequently also emotional relationships (Fobair & Spiegel, 2009; Kuo et al., 2008; Sbitti et al., 2011; Taylor et al., 2011). Side-effects of chemotherapy and hormonal therapy such as nausea, fatigue, weight changes, hair loss, premature menopause and lower oestrogen levels may all contribute to sexual problems with some of the symptoms acute and short term and some lasting long after chemotherapy treatment ends (Emilee et al., 2010; Hummel et al., 2015; Kuo et al., 2008; Reese et al., 2010). Surgical scarring and the loss of a breast, coupled with lymphedema are further sequelae that can impair a breast cancer patient’s body image (Katz, 2005; Rosenberg et al., 2012).

*Patient II* said that there was little change in their sexual functioning:

*“...I think we always had a good sexual understanding even before the cancer and our sexual communication was good”*. She said that, although she still felt tired at times, their intimate relationship was as good as ever and that they had *“normal sexual activities”*, also saying it made her feel ‘normal’ and still wanted by her husband.

Her score on the FSFI (Female Sexual Function Index) was 51.8 which indicated that she did not suffer from a female sexual dysfunction (a score  $\leq 26.55$  is classified as FSD), which corresponded with what she said during the sessions regarding her sexual functioning.

*Patient III* had previous sexual problems (before the breast cancer diagnosis) due to marital difficulties and physical conditions. Both her and her husband suffered from chronic diseases that were not under control. During the very first session she spoke about their sexual problems and lack of intimacy. She asked whether it would be possible to talk about it during our sessions and if we could try to work something out to make their sex life better.

This patient has scored 19.6 with the FSFI scale, which fell in the range of female sexual dysfunction. This agreed with her sexual functioning at the time and which she also experienced.

Patient I said, regarding her sexual functioning,

*“...survival was foremost in my mind and I was in survival mode, only wanting to get well and healthy again. I only concentrated on my treatment and surviving every day. ...although sex was not a big priority we still had a good sex life and it did me good when it happened”*.

This was verified in literature by Katz (2005) and Taylor and colleagues (2010) stating that sex is not necessarily a priority in the period immediately after a cancer diagnosis due to overwhelming emotions and concerns regarding mortality.

She and her husband never had any sexual problems before the cancer, *“...but after the treatment I experienced severe problems in that area and saw it as a huge loss”*, saying:

*“...another loss for me was the lack of oestrogen which made a huge impression on my emotional and sexual wellbeing”*. She explained that she was completely overwhelmed by the unexpected sexual changes during and after the cancer treatment with no knowledge of how to handle it. She also presented with a low score on the FSFI scale, less than 26.55, which indicated sexual dysfunction in all the areas of sexuality.

*Patient IV* experienced her weight gain as the biggest effect on her self-image and sexual image, as well her tiredness and listlessness and she requested that we make self-image a therapeutic goal in a next session. Both she and her partner felt that everything during the cancer treatment was “swallowed up” by the depression and her extreme experience and fear of depression. The patient only ever talked about anything regarding sex, when she was asked. Her emotional turmoil was her biggest “reality” and that the symptoms of depression overruled her sexual functioning. This was reinforced by authors stating that psychological distresses, such as depression as a cancer treatment side-effect, can have a profound effect on sexuality, sexual confidence, performance anxiety and lack of sexual desire (Laumann, Paik, Raymond & Rosen, 1999; Graziottin & Leiblum, 2005; Sbitti et al., 2011). Her score on the FSFI scale was very low, indicating a sexual dysfunction in all the areas that was tested, and agreed with her lack of sexual interest or activity during the time of the study.

When *Patient V* talked about her sex life the first time during our sessions, it had been two weeks after her hysterectomy and they had to withhold from sexual intercourse. She said that before her breast cancer they had a good and active sex life and were sexually very compatible, even after the diagnosis:

*“...we had carried on with our usual sexual functioning after the breast surgery and before the hysterectomy. I think that he is currently okay with my body but after the breast reconstruction he hasn’t touched my breasts yet because of the pain.”* She said that they had not discussed her illness or their sexual activities since her diagnosis. She said that there were changes in the way her body reacted to sexual stimuli and also in the frequency of their sexual activities.

Because of her hysterectomy and sexual abstinence, we had agreed that she would fill in the questionnaire as how their sexual activities and her sexual functioning were before the hysterectomy. She scored a 33.1 which was well above any sexual dysfunction and which matched what she said about their sexual functioning.

- **(Sexual) Self-image**

Breast cancer patients are exposed to changes in their physical appearance such as the loss or disfigurement of one or both breasts, lymphedema, scars from surgery, and skin changes related to radiotherapy, where chemotherapy or hormonal treatment often lead to alopecia, weight increase and menopause (Dean, 2008; Falk et al., 2010; Krychman & Katz, 2012; Kuo et al., 2008; Reece et al., 2010; Sbitti et al., 2011). These physical changes can result in altering the breast cancer patient's self-image, sexual identity and efficiency (Hummel et al., 2015; Krychman & Katz, 2012; Sbitti et al., 2011; Surbone et al., 2013).

*Patient II* said the most positive thing concerning their sex life was that her husband had told her after the latest surgery that the loss of her breast and hair had no negative effect on him and that he feels sexually the same about her and that she must please never doubt that. She said because of her husband's "soft approach" regarding their sexual side she does not feel ashamed about the absence of her breast or even the scar. She said from the very beginning, when her hair started to fall out, he had told her that she is still attractive to him. She said even undressing in front of her husband did not make her uneasy:

*"...because I feel more comfortable with my body I even allow him to touch my scars or massage my sore arm".*

*Patient III* did not have concerns about her body image at the time of this study, but their sexual problems were more because of their health problems and general marital problems than that of a changing or altered self-image because of the cancer treatment.

*Patient I* said: *"...my whole self-image has changed due to the fact that the form of my body and weight have changed drastically...even the way my body reacts*

*sexually has changed,...I don't reach an orgasm anymore and it is as if my body doesn't want to react in any sexual manner after the treatment. ...I don't understand my body in terms of my sexuality anymore."*

*Patient IV* has revealed that she never had a good self-image and that because of her weight gain and scarred breast, she felt even more self-conscious about her body, especially when she was naked and that it also effected their sexual interaction. She said that her breast looked different from the other one where they did the lumpectomy and that even with clothes you could still see the difference. She said it bothered her so much that she was even considering breast reconstruction where she never thought about it before. This was supported in literature which stated that negative perceptions of body image amongst breast cancer survivors comprise dissatisfaction and unhappiness with physical appearance, reluctance to look at oneself naked, feeling sexually unattractive and self-conscious about surgical scars and appearance (Fobair et al., 2006).

*Patient V* said that because of their young age and the fact that they were very active sexually;

*"...I was scared in the beginning when I realised that my body were going to change and that he might be repulsed by my changed body."*

This fits in with statements that all current cancer treatments for breast cancer can cause changes in the female body that abruptly affects sexual functioning and emotional relationships (Fobair & Spiegel, 2009; Kaplan, 1992; Sbitti et al., 2011), and because of her fear that her husband might reject her sexually she has decided to have reconstruction surgery as soon as it was possible. She said:

*"I didn't want my husband to see me without breasts, it is important to me that my husband sees me as a woman and I would go to any lengths to restore my body image".*

She said she realised that her husband had experienced the idea of her hair falling out very negatively and that he didn't want her to walk around without her wig and she felt that he was ashamed and embarrassed of her cancer and looks, saying *"...it made me feel more vulnerable and alone"*.

This was accentuated by Klaeson and colleagues (2011) saying that the loss of femininity, libido and satisfactory intercourse can cause emotional distress which in turn can affect the women's already vulnerable transition towards redefining their sexuality.

- **Sexual communication and intimacy in the relationship**

As couples cope with cancer they often experience a lack of communication about changes to their sexual relationship or sexual problems that might emerge due to the cancer treatments and which can cause emotional distancing and marital dissatisfaction (Manne et al., 2006; Milbury & Badr, 2013). During illness and stress most couples find it hard to talk about sexual problems and it is common for a person with a life-limiting illness to be less intimate or trusting during the crisis phase of her illness (Hordern & Currow, 2003; Murray, 2010). The American Cancer Society (2013) stated that it is eminent that clear two-way communication about sexual matters is the key in adjusting sexual routine when cancer changes the body and adjustments had to be made. It is an important task for couples to resume an intimate relationship to help them draw on this connection as a source of strength and support (Manne & Badr, 2008; Nicolas, 2013).

*Patient II* experienced that their relationship, sexually and otherwise, was close before the cancer and is now even closer, which is confirmed by Sheppard and Ely (2008), who said that a cancer experience can enhance a greater sense of closeness in a relationship.

*Patient III*, when asked about her sex life, answered that she is still feeling that her husband is not supporting her the way she would have liked and that he does not understand her emotions and fears, saying:

*"... our sex life is not that good, but we had problems from before the cancer, we both have chronic illnesses and my husband has once even attended a 'man clinic' but it didn't help him."* She also said:

*"Me and my husband don't talk about sex or even intimacy..."* Sheppard and Ely (2008) have confirmed this by saying that a breast cancer diagnosis can bring up pre-existing marital problems to the fore-ground. During a session with her



husband he has confirmed that they do have a problem with their sex life and that his physical illness, which is not under control, plays a big part in it.

*Patient I* experienced the lack of intimacy between her and her husband as yet another loss, she felt that she did not have the proper knowledge regarding the cancer and her sexual functioning and she did not communicate her lack of sexual interest and overall sexual changes, properly. She said:

*“... the lack of communication between me and my husband then led to absence, not just in sexual functioning, but also in intimacy.”* Ussher and colleagues (2012) underlined the fact that a cancer diagnosis can change the relational dynamics between a couple which can affect the sexual relationship and that couples living with cancer have reported communication problems or increased conflict that can contribute to relationship breakdown.

*Patient IV* said that she and her partner do not discuss the impact of her cancer and premature menopause on their sexuality at all;

*“...but yet, we always make an effort with our sexual and intimate relationship, but I would like to hear what he is saying about our sexual relationship.”*

She explained during a joint session that both of them actually experienced a low libido that was present before the cancer, but also emphasized that they don't see it as a problem or crisis because they have a very good intimate relationship. They were very close to each other and held hands and touched each other often, this was noticeable during our session. She said that having said that, she would like them to work harder at their sexual relationship and improve it, for she thinks that with a more regular and satisfactory sex life,

*“... it can enhance and strengthen our relationship and even my self-image”.* Her partner said that the changes in her body have no effect on him or the way he feels about her sexually or otherwise.

*Patient V* said she was angry and disappointed in her husband because of the fact that she didn't experience him as supportive during the time that she needed him the most, especially during the chemotherapy. She felt that there wasn't much

intimacy between them which was hard for her to understand and endure because before the cancer they had a very good and special sexual bond between them. Because of his lack of interest and indifference towards her and her cancer she developed feelings of resentment towards him, saying:

*“...the cancer is currently standing between us”*. This was confirmed by Ussher and colleagues (2012) underlining the fact that a cancer diagnosis can change the relational dynamics between a couple which consequently can affect their sexual relationship.

### **Theme 7: The menopausal factor: The breast cancer patient’s experience of it:**

Menopause is an occurrence outside the normal life course and chemically induced premature menopause is one of the most unexpected and sudden side-effects of chemo- and hormone therapy which can influence the breast cancer patient’s quality of life through biological and psychological changes (Brem & Kumar, 2011; Deeks et al., 2011; Ewertz & Jensen, 2011; Hummel et al., 2015; Kuo et al., 2008; Mok et al., 2008).

*Patient II* did not experience a lower libido during her treatment and when asked about menopause, she said that she was not menopausal before the treatment, although expecting it to happen at any time:

*“...Nobody had up till now spoken to me about menopause or even the possibility of menopause or any symptoms because of the treatment and I am not sure what to expect of it or that it might even happen now. ...if this is the case, I would like to know more about it, because I am still pre-menopausal”*.

She said she realised that she was at the age where the symptoms of menopause would start and she did not feel negative about “normal” menopause, she just wanted to be ready. Reece and colleagues (2010) underlined this by saying that even during treatments, such as chemotherapy, the patient and her partner can still have intimacy and sexual needs and that maintaining sexual activity can be a sign of overall wellbeing as well as the ability to cope with the cancer and its treatment.

*Patient III* was the only patient that was in complete natural menopause and was very comfortable about this status. She said that although her sexual issues was not just cancer related, some of their sexual problems were also because a lack of sexual communication.

The therapeutic sessions with *Patient II* and *III* (who were still busy with their treatment) were more focused on their emotional status and experiences, current chemotherapy and new information regarding cancer treatment and the upcoming surgery and their anticipation anxiety, with less information about treatment related sexual functions. This fitted in with literature stating that because of the trauma of the diagnosis of cancer and the accompanying survival mode that kicks in as well as the busy treatment schedule, sex is not necessarily an immediate priority for the patient (American Cancer Society, 2010; Katz, 2005; Taylor et al., 2011).

*Patients I, IV* and *V* have developed chemically induced premature menopause due to their cancer treatments with outspoken symptoms such as hot flushes, weight gain, negative body image, little or no sexual desire and changes in their sexual responsiveness and functioning. This was supported by authors such as Derzko and colleagues (2007) and Deeks and colleagues (2011) stating that breast cancer patients experience fears and uncertainties and sexual changes that accompany the symptoms of premature menopause.

*Patient I* reported a complete lack of oestrogen because of her menopausal status, saying:

*“...I now have a much ‘older’ body that I must get used to ...I was not prepared for the severe symptoms and suddenness of the menopause and it made a huge impression on my emotional wellbeing and sexual relationship with my husband ...it was completely unexpected.”*

Both she and her husband were of the opinion that they were not properly informed about the changes due to premature menopause, especially the changes in their sexual functioning during and after the treatment. They didn't understand the complete lack of sexual drive and that it was so specifically related to menopause and cancer. Both of them agreed that her lack of interest in sex

contributed to their feelings of uncertainty about themselves as sexual partners and the development of her lower self-image.

*Patient V* also felt that although her oncologist had explained the principle of menopause to her, she still needed more information regarding the symptoms of menopause especially for the next five years when she must use the hormone medication, saying:

*"I know it will influence my sex life, but how and to what extent? I need more time to talk to somebody about menopause and my perceptions and emotions regarding it.... menopause is something completely unfamiliar to me"*.

*Patients I, IV* and *V* complained about severe and uncomfortable hot flushes, insomnia and lack of vaginal lubrication which were affecting their sexual functioning and sexual relationships. *Patient V* said because of her recent hysterectomy they are not currently engaging in sexual activities, but experienced a very low libido which developed recently and which is unfamiliar for her, saying:

*"...I am young and sexually active and don't understand my lack of sexual interest"*.

This was supported by a study done by Deeks and co-workers (2011) that breast cancer patients with premature menopause has reported a lack of information and support in this area from their oncology team

*Patient IV* said she was still completely pre-menopausal before the chemotherapy and is not sure of what to expect of menopause. She is not on a hormone treatment and her menses has started one month after her last chemotherapy where she experienced a very bad PMS episode, but was so thankful when she realised that it was PMS and that everything *"is back to normal and not my depression that was going worse."* This was explained by Brem and Kumar (2011) saying that chemotherapy related amenorrhea can be temporary in pre-menopausal breast cancer patients.

All three patients have received information regarding treatment-related premature menopause from their oncologists, but all three of them specifically requested

more time to talk about it and what exactly menopause meant in terms of practical and sexual implications.

#### **7.3.1.6 Work functioning**

Studies have shown that decisions about working during and after cancer treatment are influenced by personal choice, the meaning of work for the individual and economic considerations (Kennedy et al., 2007; Shewbridge, Wiseman, & Richardson, 2012).

#### **Theme 8: Working or not working (while receiving chemotherapy):**

Working is important for an individual's identity and sense of feeling valued. It provides a re-integration into society and offers a distraction. Returning to work, therefore, has the potential to help the cancer patient to regain a sense of normality and control and enhance the patient's quality of life and psychological well-being and is seen as a symbol of recovery (Kennedy et al., 2006; Mehnert, 2011; Peteet, 2000; Raque-Bogdan et al., 2012). For breast cancer patients particularly, going back to work can be affected by anxiety about their physical appearance, chemo-induced cognitive impairment and chemo fog which can all impact their confidence in carrying out their work tasks (Munir et al., 2010). 'To work or not to work' varies from patient to patient where some choose to take time off from work during their treatment, while other patients continue part-time or fulltime employment depending on the type of cancer and treatment, the type of work and financial necessity (Short et al., 2005; Spelten et al., 2003). When to go back to work is an area that needs to be addressed by the oncology team and Kennedy and colleagues (2006) felt that an improvement in communication about readiness to return to work and issues such as side-effect management would be advantageous for the cancer patient.

*Patients I, III, IV and V* had full time careers during their cancer treatment. *Patient I* stayed at home, where both *Patients IV and V* continued to work throughout their cancer treatment. It was noticeable that *Patients IV and V* put a high value on working and participating in work related activities throughout their chemotherapy and the benefits that they have felt from that and that *Patient I*, who had chosen

not to work had experienced much more negative effects feeling hopeless and with too much time on her hands to think and experience negative thoughts.

*Patient I* hasn't work for the whole time that she was receiving chemo and radiation therapy, saying:

*"The treatment was too radical for me and I was too tired to work and my focus was not on the work at all... but not going into work every day also made me feel aimless and out of contact with reality,... not being able to work was very hard for me and made me feel inadequate and depressed because my work plays a big part in my life and identity ...I felt aimless and out of contact with reality..."* also saying: *"on the positive side of staying at home was that it helped me to regain my strength and energy ...I didn't have any work related stress which was good for my body and mind"*.

The fact that she didn't work made her feel more isolated and she had more time on her hands for negative and destructive thoughts. She went back to work a year after her diagnosis and treatment was finished and is currently working full-time again, saying:

*"...I am managing my working hours better and more user friendly than before the cancer."*

*Patient III* who worked in a care facility felt that she was not capable of working during her treatment, not emotionally nor physically, saying:

*"I have a very physically demanding job and feel just too tired to do my job properly."*

She was in the process with the social worker to arrange for a temporary absence of leave from her work because she felt she could not handle work-related stress then, yet it also stressed her out because the whole family was financially dependent on her income. She did not know whether she would go back to work or not, saying that this was not a big priority for her now. She wanted to get well first and get the treatment and surgery out of the way. Spelten and colleagues

(2003) have supported this by saying that cancer-related fatigue can affect employment by increasing absence from working.

Because of the increased use of more intensive chemotherapy treatments over longer periods of time, the need to continue to work whilst receiving treatment, has become more pertinent (Shewbridge et al., 2012), and it is estimated that up to 62% of cancer patients continue or return to work during or after treatment (Spelten et al., 2003). This was applicable to *Patients IV* and *V* who continued with working during their treatment.

*Patient IV* only took off from work the day on which she received the chemo and the day after that. She saw herself as a very career orientated and driven person and her work played a large and important part in her life and identity, she said:

*“...my work entails a lot of concentration and focusing and in the beginning with the chemotherapy I was constantly scared that I would not be able to do my work properly. ... I rely heavily on my intellect.”* She also said:

*“The fact that I could work every day had saved me, it kept me sane and busy and I could focus away from my cancer and anxiety. ...Being so involved in my work was one of my coping skills.”*

She was dependent on her salary and because she did not have a medical aid she needed her salary to cover her medical costs. She was scared of not being able to do her job properly because she was depressed and tired all the time and struggled with a lack of concentration and memory. Because of this, she could end up jeopardising and losing her job. This is not an unrealistic fear. Literature confirmed this by saying that there can be the possibility of potential job loss due to the demands of the medical treatment and on-going side effects of treatment (Spelten et al., 2003). Although she worked the entire time while she received her treatment, there were times that it was hard to “juggle” the work and the chemo and the side-effects. She said she tried to go in every day, even the days that she felt ill, so that she could stay busy and be surrounded by people. Literature explained that functioning properly in your job, represents normality and routine after your illness and treatment and symbolises hope for the future while providing

access to social support, medical insurance and financial resources (Kennedey et al., 2007; Maunsell et al., 2007; Shewbridge et al., 2012).

*Patient V* worked right through her chemotherapy and always tried to schedule her chemotherapy on a Friday so that she didn't need to take off from work. The longest that she took off was the six weeks after the hysterectomy. She said:

*"I was constantly scared that my energy and concentration would fail me. ...I could see that especially my energy levels and concentration and memory were not the same, but have tried to work around it"*.

Three months after the last treatment she reported back during one of our therapeutic sessions that her tiredness and concentration was getting better and that she could keep up with her demanding job:

*"...this makes me feel worthy as a worker again"*, but six months later, with our last therapeutic session, she complained that she struggled again with concentration and lack of short term memory:

*"...it is a serious problem for me, I cannot remember things and it affects my marriage and work. ...I work with figures and have a responsible job and am scared that I will make mistakes and can lose my job. ...I need the salary and cannot afford to lose it"*.

Munir and colleagues (2010) confirmed this statement, indicating that women treated for breast cancer reported experiencing cognitive impairments and often struggled with short-term memory that affects their working life. In spite of *Patients I, IV* and *V's* fear of not being able to do their work properly or losing their work, there is evidence that cancer survivors are still productive and perform well in the workplace during and after treatment (Bradley & Bednarek, 2002).

I have observed that the breast cancer patients in this study found it important to be able to continue with their careers during their treatments and strive to do their jobs properly in spite of treatment side-effects that directly influence their jobs or ability to do their jobs. The reasons seem to be on the one hand to ensure them that they don't lose their jobs and with it their financial security, but also to "keep



them in the loop of normality” and help them to focus on something else than their illness. It seems that more physical job requirements (as with Patient III) are harder to adhere to as a more passive “desk” job.

Another reason I found for wanting to go to work as often as possible was the support that they got from their colleagues, which they all found very lenient and accommodating, making it possible for them to continue working throughout their treatments. The support and acceptance from their colleagues gave them courage to carry on with their “normal” lives during their treatments. Literature confirms that the support from employers in facilitating the patient to return to the workplace after treatment has an overall effect on the cancer survivor (Bouknight et al., 2006; Holgrem & Evanoff, 2007; Shewbridge et al., 2012).

#### **7.3.1.7 Social support: the family system**

Social support refers to help and encouragement which can be practical and/or emotional from family or friends that improve and boost the receiver’s self-esteem or provide stress-related interpersonal support and is a critical ingredient to physical and mental health when facing cancer care (Kim et al., 2011).

#### **Theme 9: Effect of breast cancer on the family and marriage:**

According to Sutherland (1957) and Grassi (2013) understanding the cancer patient and her family is the foundation for a holistic development in cancer care and that both the patient and the family can benefit from psycho-oncology care (Haber et al., 1995). Stressful effects of breast cancer extends beyond the patient into the lives of their family members, making them second-order patients who respond to the strain of cancer as interdependent, emotional beings (Lethborg et al., 2003; Nicolas, 2013; Norhouse et al., 2005). With the diagnosis of cancer, as was seen in this study, families were launched into an unfamiliar environment where they often did not have the knowledge, either emotionally or psychologically, to absorb and integrate the illness into their lives and healthcare systems. Oncology teams are not always aware of the impact that the cancer has on the family milieu (Baider, 2008). Family members play a prominent role in the cancer patient’s life, from the acute stage of treatment, to the extended and permanent stage (Mullan, 1995).

Apart from the family angle, it is important to view cancer from a relationship perspective as well. The partner of the breast cancer patient in particular, will be critically affected by the diagnosis and treatment and according to literature, there is considerable proof that relationships can experience substantial stress during this crisis time (Manne & Badr, 2008; Nicolas, 2013; Sheppard & Ely, 2008; Walsh et al., 2005). The partner of a breast cancer patient has to cope with challenges such as worries about the potential loss of their life partner and providing emotional and practical support and therefore needs relevant information and support from the psychologist, as many will feel uncertain and at a loss about what to expect while their partner undergoes treatment (Dean, 2008; Harrow et al., 2008).

*Patient II* said: “...what got me through the diagnosis and the chemotherapy was the closeness and constant support of my whole family, they made sure that I was okay and that I ate properly every day. ...I don't know what I would have done without them, their persistent support and my belief and religion literally pulled me through the healing process.”

She experienced good and strong support from her family from the very beginning, saying:

*“...this was the pattern we had before the cancer. ... we all spoke openly about my cancer; they also encouraged me to keep myself busy and to stay positive.”*

This patient had, during the course of the session, often commented on the support of her family, especially her husband and how it had strengthened her. She said that from her side she had, in the beginning with the start of the chemotherapy, often felt guilty about not being able to do for them what she was used to do before the chemo. Savard and colleagues (2005) confirm this by saying that cancer patients often feel like a burden to their family, no longer useful to them. Research has further demonstrated positive effects of social support on physical as well as psychological welfare of people suffering from chronic illness such as cancer and lower degrees of depression and other negative moods caused by physical illness, which was evident in this patient (Kim et al., 2010).

*Patient III* was the only patient who had experienced a severe lack of support both from her husband and children, especially in the beginning after the diagnosis of her breast cancer and during the chemotherapy. She strongly felt that her husband did not understand her emotions and fears and didn't support her the way she felt he should have, saying:

*"...for a while I resented him for not supporting and trying to understand me better."* She was also very disappointed in her children for not making more effort to support her and help her with practical matters during her treatment saying:

*"...I lay it at the door of our poor relationships before the cancer. ...we as a family don't have good communication skills and haven't spoken of the cancer yet and I feel I need to talk to them about it. ...I am worried about the absence of my children in my life. ...I need them".*

She has asked if it was possible to see her husband and explain to him her emotions and what she was going through. It appears that the lack of emotional support and communication has increasing negative effects on a person's health and survival and aggravate psychological distress and decrease marital satisfaction and that supportive relationships are important for well-being when under stress (Hordern, & Currow, 2003; Milbury & Badr, 2013; Murray, 2010). Later through the course of her treatment and therapeutic sessions, the relationships between her and the children and her husband improved. Her feedback was:

*"...with my surgery I was so stressed and my husband has supported me very well. ...for the first time me and my husband had a much better relationship with each other and we spoke more about our emotions. ...I feel more understood by him. ...the one positive thing about the cancer is the better relationship between me and my husband."*

Both *Patients I* and *V*, who had young children at home, were worried about the effects that their cancer had on their families and especially their children, worrying excessively about leaving their children behind and feeling guilty about not spending enough time with their children.

*Patient I* said “I was not able to do my everyday tasks for my husband and children on the days that I felt sick and tired. ...my children have busy school and sport schedules and I was not actively involved with them. Although I was at home during the treatment, I felt less available for my children and it made me feel hopeless not having enough energy to do anything at all”.

She realised that the cancer affected the whole family and that they had to work together to accommodate the long term effects of the cancer. As a family they were very supportive of each other and engaged in a lot of activities together. She also said:

*“My husband was very supportive of me during the entire time of the treatment and we were both very focused on the practical workings of the household to ensure that the effect on the children were minimal”.* She experienced that her husband often felt hopeless for not being able to help her with her illness and emotional struggle, not knowing how to do it. She said:

*“I had an extremely good support system in my husband and mother and close friends, they supported me very well during the treatment and now. ...it was the one thing that kept me going”.*

*Patient IV* stated that she was supported from the beginning by her family and life partner. She said that because of her severe depression, although the support was there from friends and family, she had isolated herself and would rather have been by herself than with other people, saying further:

*“Because I am such an independent person, the fact that I was so tired has confronted me to be in the position to have needed the assistance of other people. ... this ‘dependency’ on other people made me feel vulnerable.”* In spite of her depression and feelings of isolation, she also said that the constant support from her partner was what kept her going.

Psychological research support this by stating that people are often reluctant to ask for help even when it's needed and agrees that people in need of support underestimate the willingness of others to help (Flynn& Lake, 2008; Skeels et al., 2010).

*Patient V* confirmed that her fear of dying revolved around her child and that every decision that she made was with him in mind.

This extreme fear of young mothers are underlined in the literature where it has been proposed that one of the reasons young mothers with breast cancer experience more overall fear for recurrence and dying, is that of leaving their young children behind (Connell et al., 2006; Lebel et al., 2013). During her treatment she had been only a little involved in her child's day to day caretaking, leaving her with a lot of feelings of guilt and sadness. She said even then, after the treatment she could not keep up with him because of her on-going tiredness. It worried her that he was still not back to where he was before her diagnosis in terms of his behaviour and developmental tasks. There was a clear indication that his behaviour had regressed during the time that she was ill. She said:

*"Just thinking or talking about my son makes me depressed and sad."*

Literature states that parents with young children in particular, experience more intense and invasive fears and guilt feelings about potentially abandoning their children than that of older patients. They also have more family responsibilities therefore they are more likely to report that their illness and treatment interfere with important roles and activities than might be the case in older women (Brennan, 2001; Ganz et al., 2002; Lebel et al., 2013; Rauch & Muriel, 2004).

*Patient V* experienced that her and her husband's perceptions and expectations of support was completely different, saying:

*"...my mother was more involved and supportive during the whole treatment process than he was."* She felt that he didn't make an effort to try to understand the cancer or her emotions and she felt that the cancer was standing between them, stating:

*"...if we fight now he would refer back to that period when I was busy with my treatment, blaming me that I was irritable and abrupt toward him and my son ...during that period and even now we don't discuss the cancer with each other."*

She said that even after the treatment they were not at a good place with each other and that she felt resentful towards him. Beecham and colleagues (2005) support this in saying that only through open communication can the family make plans that accommodate the likely course of the illness and make the most of the situation. She said her mother and grand-mother was a big emotional support for her during her whole life and especially during the cancer and cancer treatment and that she relied heavily on them.

### **7.3.1.8 From breast cancer patient to breast cancer survivor:**

#### **Theme 10: Breast cancer as a chronic disease: the patients' understanding of it:**

Cancer, like most chronic illnesses, carries a high risk for emotional- and sexual dysfunctions due to chronic symptoms like fatigue, neuropathic pain, cognitive impairment and menopause (Backonja, 2003; Carpenter et al., 2009; Nusbaum, Hamilton & Lenahan, 2003; Richards, Bertolotti, Doss & McCullagh, 2011). After the end of active treatment the survivor becomes aware of and learns to live with the chronic side effects of the illness and its treatment and attempts to adapt to the long-term changes and demands needed for adjustment to chronic illness (Anderson, 1992; Livneh, 2001).

Patients II and III were both still busy with their treatment (radiation therapy) when we ended our sessions, but understood through our conversations that the side-effects of the surgery and the chemotherapy can continue well into survivorship. Both of them were still experiencing prominent side-effects of their chemotherapy (pins and needles in their feet and hands) and severe tiredness and chemo fog.

*Patients I, IV and V* experienced the chronicity of their breast cancer in the prolonged side-effects of their chemotherapy and surgery and the anticipation anxiety before follow-up tests and consultations with their oncologists.

*Patient I* said:

*"I never thought about breast cancer as a chronic disease. ...I only started to understand the treatment's side-effects better after the cancer treatment, living with it on a daily basis. ...I think that having understood it better and in a more*

*knowledgeable framework, I could have coped better with the whole journey, I now realise that for the rest of my life I will be confronted with the 'aftermath' of cancer and although the cancer is in remission the 'cancer file' in my brain will never be deleted...the psychology of the cancer will always stay with me in the form of the permanent changes of my body and sexuality."*

Patient IV felt that after the treatment her anxiety was worse than during the actual treatment phase where she suffered both from depression and anxiety, saying:

*"...I am still experiencing side-effects of the cancer treatment. ...I wasn't prepared or expecting it to last so long after the end of the treatment...currently the tiredness is the worst.*

Patient V experienced symptoms of depression only after the treatment while in the remission phase:

*"...I feel very badly depressed now, because of our marital problems because of my cancer."*

She experienced the tiredness, lack of short term memory and lack of concentration and sexual dysfunction as the worst on-going side-effects of her cancer. She understood that the chronicity of the illness would carry on. She realised that apart from the treatment side-effects using the hormone therapy medication for the next 5 years would entail 'living' the active side-effects from that. She said:

*"...I will have to go for lifelong follow ups and tests that will make me anxious and scared."*

According to literature, breast cancer survivors often report that they were unprepared for the complex rehabilitation process and persistent symptoms of depression or anxiety after the end of their treatment (Brem & Kumar, 2011; Burgess et al., 2005; Dolbeault et al., 2009; Reyes-Gibby et al., 2012).

### **7.3.2 The shift from cancer patient to being a "normal" person again**

Although the end of treatment seems like a time for celebration, which it is, it is also a stage full of its own distresses and challenges such as not knowing what to

expect after the end of treatment, what kind of follow-ups were expected of them and which symptoms are important to monitor (American Cancer Society, 2010; Ganz et al., 2004; Golden-Kreutz et al., 2005; Henselmans et al., 2010; Stanton, 2012). The end of cancer treatment can also cause acute anxiety to the breast cancer survivor because of diminished contact with their oncologists and clinical specialists, which can leave a person with a feeling of loss to the ready access of the health care system and the safety net it provides. This often leads to feelings of vulnerability and of not feeling in control (Anderson, 1992; Ganz et al., 2004; Golden-Kreutz et al., 2005; Stanton, 2012). This end of treatment anxiety was clearly seen in the sessions with the three patients who were already finished with their treatment for a while.

*Patient I* supported this by saying:

*“...after the end of my treatment when I thought I would be glad and happy, the anxiety was bad again ...the shift from a cancer patient to ‘nothing’ was difficult for me ... all of a sudden I felt vulnerable and unsure of myself.”*

*Patient IV* said:

*“...I didn’t know how to proceed from a cancer patient to a ‘normal’ life again, I got so used to the cancer schedule and the interaction with the oncology team and the co-cancer patients, it made me feel safe and secure ...I don’t know exactly where I belong now, I am in remission, yet I still have physical symptoms of the treatment and I have to go back for a follow-up session next month. ...it feels as if I am still busy with cancer.”*

*Patient V* said it felt as if her cancer experience was something of the past for her family and friends,

*“...but I still need to talk about my cancer experience from time to time to somebody but I don’t think they would understand this need of me to talk about the cancer after everything is finished and I am cancer-free. ...I can understand that ‘outside’ people cannot understand the change from a cancer patient to a normal person again.”*



This is underlined in literature stating that family and friends can assume at the end of the treatment that the cancer experience has been resolved and that their involvement and support is less needed resulting in the cancer survivor feeling abandoned and lonely (American Cancer Society, 2010; Burgess et al., 2005; Dolbeault et al., 2008; Henselmans et al., 2010). Certain authors even suggested that breast cancer survivors are in their highest need of interpersonal support after completing their treatment but often find it unavailable (Ganz et al., 2004; Stanton, 2012; Wurtzen, 2013). Ganz and co-workers (2004) summarised this by saying that patients are often overwhelmed and disappointed in themselves to still experience chemotherapy-related and mood problems months after the end of their treatment, especially if they felt that they have coped well during the treatment.

## **7.4 CATEGORIES AND THEMES: INDIVIDUAL PSYCHO-ONCOLOGIC INTERVENTIONS**

Individual therapy was already defined in the literature chapter as a formal process of interaction between a trained therapist (in this case the researcher) and a patient (the selected breast cancer patient and participant) working in a safe and confidential environment to enhance the psychological well-being of the patient (Wedding, 2010). I have chosen individual treatment sessions because it allows for the breast cancer patients' unique physical and psychological needs and is suitable for the cognitive-behavioural techniques that were used in this study (Beltman et al., 2010; Savard et al., 2005).

### **7.4.1 Presentation and interpretation of the categories and themes**

The analysis of the individual psycho-oncologic interventions will now be presented into core categories and then into themes 11 to 21 in Table 7.3.

The psycho-therapeutic interventions and process of Table 7.3 will be discussed below with a distinction between psycho-therapy and sex therapy interventions. There will also again be a distinction between Patients II and III who were still active with their cancer treatment during the therapeutic sessions and which will be discussed together and Patients I, IV and V who were already in remission and will also be discussed together.

**Table 7.3: Categories and Themes of the Psycho-Therapeutic Interventions with Breast Cancer Patients:**

<b>CATEGORIES</b>	<b>THEMES</b>
<b>Emotional catharsis</b>	<b>Theme 11: Emotional Expression: allowing, acknowledging and understanding their negative emotions and thoughts and encouragement to talk about it in therapy.</b>
<b>Psycho-education</b>	<p><b>Theme 12: The power of knowledge: Explaining breast cancer treatment related phenomena, including depression, anxiety, fatigue and pain.</b></p> <ul style="list-style-type: none"> <li>• Normalizing emotional experiences</li> <li>• Changing from ‘cancer patient’ to a ‘post cancer status quo’ and coping with permanent changes regarding the chronicity of breast cancer.</li> </ul>
<b>Cognitive and behavioural therapy</b>	<b>Theme 13: The Acceptance and Adaptation process</b>
<b>Sex therapy:</b>	<b>Theme 14: Different Cognitive and Behavioural techniques</b>
<b>Talking about sex</b>	<b>Theme 15: Talking about sex: Why cancer patients don’t talk to their oncologists about their sexual issues and where and to whom can they talk about it:</b>
<b>Sex therapy: psycho-education and behaviour and cognitive techniques</b>	<p><b>Theme 16: Explaining and educating the most prevalent and relevant sexual matters:</b></p> <ul style="list-style-type: none"> <li>• Menopause and low libido and the impact on sexual functioning</li> <li>• Sexual self-esteem and body image</li> <li>• Behavioural changes and cognitive restructuring</li> </ul>
<b>Couples and sex therapy</b>	<b>Theme 17: Couple’s Intervention</b>

	<ul style="list-style-type: none"> <li>• Sexual and Emotional issues</li> <li>• Communication</li> <li>• Long term changes</li> </ul>
<b>Patient feedback (general):</b>  <b>END OF THERAPY</b>	<b>Theme 18: Patient's feedback from the therapeutic sessions.</b>

#### 7.4.1.1 EMOTIONAL CATHARSIS

It is important for therapists to support and encourage direct expression of negative emotions like fear, anger and sadness in a safe and empathetic environment. This will not only lead to releasing of unexpressed emotions, but will allow patients to adapt healthier thought processes and diminish the risk of psychopathology (Giese-Davist et al., 2005; Stanton et al., 2000; Thornton et al., 2014; Yoo et al., 2014).

#### **Theme 11: Emotional expression - allowing, acknowledging and understanding you're patient's negative emotions and thoughts and encouragement to talk about it in therapy:**

In the light of the fact that emotional distress has lately been defined as the sixth vital sign in cancer care, and that it plays a dynamic role in treatment outcome, various authors have verified that emotional expression during therapy can positively affect a patient's psychological well-being. Emotional expression allow the breast cancer patients to be aware of their feelings and cognitions, deal with it and become aware of choices they can make to lessen some of their distress (Conley et al., 2016; Drageset et al., 2010; Giese-Davis et al., Low, et al., 2006; Pinguart & Duberstein, 2010). Thinking, talking and writing about emotions can make emotional experience less intensive and invasive and can increase insight into why emotions are experienced and how their effects can be reduce (de Ridder et al., 2008). Working with breast cancer patients, I supported the importance of implementing emotional catharsis as will be described below.

*Patients I, IV and V:* who were finished with their oncology treatments, and who did not share much of their emotions with their oncologists during their diagnosis

and treatment period, confirmed during their sessions a huge relief in sharing their emotional experiences.

*Patient I* said that she already experienced emotional relief in answering the questions during the first two sessions:

*“...remembering all the emotions, I still have a very prominent need to talk about my experience and emotions regarding the cancer treatment and how my family has experienced it.”*

She said that she did not speak a lot about her emotions during the treatment either to her oncologist or family and that she regretted that she was not more forthcoming with her emotional experiences:

*“...I think that I would have dealt better with my emotions if I have shared it more. ...I appreciate this opportunity to talk freely to somebody with knowledge about the psychological side of my cancer it already makes me feel better and more normal. ...I am looking forward to having therapeutic sessions with you regarding my issues around the cancer and my functioning now.”*

She said that, especially talking about her fear of death, which she did not talk at all about at the time, made her feel much lighter:

*“...talking about death and my fear of dying, without feeling guilty or unthankful, gives me huge relief.”* Drageset and colleagues (2011) support this by saying that even to some degree, allowing you to experience emotions and to share it is a very helpful mechanism of coping. This patient said that if she had the opportunity to have spoken to a psychologist during her treatment:

*“...it would have saved me a lot of agony if I could learn about the cancer process and had the opportunity to vent my emotions.”*

*Patient IV* was very emotional during the first three sessions and eager to talk about how she felt. During our first session she said that she was ready to talk about how she felt during her cancer period and with very little prompting she shared her emotions and also showed a lot of emotion during the sessions. In the

process of emotional catharsis she provided me with deep and rich appropriate information. During the first session she said:

*“I feel much more emotional now after the treatment has ended than during the treatment and I cannot understand why I am feeling so emotional. ...during the treatment I didn’t have much time to dwell on my emotions for there was no time between the chemo sessions and the blood draw sessions and appointments with the oncologist and going back and forth to work to have focused on my depression and anxiety, but I am crying a lot lately and feeling very depressed and anxious.”*

She said because she was feeling so depressed during her treatment she would have liked to talk about her emotions, but because of her lack of finances she couldn’t afford to see a psychologist. She said:

*“I need to talk about my fears. ...I had never been in a similar situation before and I felt a lack of specific skills to deal with my cancer.”*

I explained to her that talking freely about her emotions will make her feel more in control and less of a victim and that expression of emotions as a coping mechanism can decrease her emotional distress and restore her psychophysiological balance (de Ridder et al., 2008; Stanton et al., 2000). She understood that through the ability of expressing emotions surrounding her cancer experience, she would be able to effectively adjust to her new “post-cancer” status quo (Stanton et al., 2000).

*Patient V:* The first and second sessions with her were predominantly emotional catharsis, she said in the beginning:

*“...I really need to talk about how I felt when I was diagnosed with cancer and throughout my treatment, especially now after the treatment was successful and I am in remission. I really thought that once I would be finished I will automatically feel better, but it is not the case.”*

She said after her cancer diagnosis and during her treatment she talked a lot about her cancer to the people around her, saying that it was her way of dealing with her emotions, but saying that:



*“I now need to talk to a professional person who will understand my situation and my emotions and give me some advice as to what to do now, not just for me but also what to do with my child and husband.”*

Barak and colleagues (2008) stated in the literature that sharing negative feelings with others has a tremendous relieving effect and can initiate a feeling of personal empowerment and improved self-confidence. One of her prominent emotions throughout her illness was that of guilt feelings regarding her husband and child, and she was now given the time to talk about it and to put it into the perspective of her illness. I explained these guilt feelings to her in the framework that mothers with cancer often lacked the ability or the strength to maintain parental roles due to factors such as severe side-effects, and then feel guilty because they still want to meet the needs of their children. They might even feel that there are societal demands on them as a woman to continue to take responsibility for child care and housekeeping during their illness, which further contributes to guilt feelings (Semple & McCance, 2010).

*Patients II and III* who were still busy with their treatments, had the opportunity to talk about their emotions regarding the cancer and anything else they wanted to talk about during the therapeutic sessions. They were both eager to share their feelings and thoughts especially regarding their chemotherapy and emerging surgery and spoke about it spontaneously. Their fears and anticipation of their surgery and their urgency to speak about it was imminent during our sessions. They explained in detail how the chemotherapy affected them biologically in terms of specific side-effects and emotionally of how it made them feel.

*Patient II* spoke extensively about the persistent tiredness from the chemotherapy which was her biggest concern and caused a lot of anxiety, saying it affected her emotional health and psyche the most. When asked about her current emotions during our third session, she said:

*“The mere fact that we speak every three weeks gives me the courage to carry on knowing that I can vent my feelings to somebody that understands the process of chemotherapy and somebody that is outside of my family. ...Speaking about the cancer and getting information about it makes it less unfamiliar and scary for me.”*

We talked about the importance for her to acknowledge her negative thoughts and worries and to allow herself to “live” through it, speak about it and put it into a realistic framework, such as her illness and treatment. I have encouraged her to speak to her oncologist regarding the cancer and chemotherapy and to ask him questions about matters that are unclear to her after she complained about not being able to talk to her oncologist and clarify certain things with him. Schlatter and Cameron (2010) strongly emphasize that if the breast cancer patient does not reveal the true severity of her symptoms to the medical staff and support system, they then may not receive sufficient advice or assistance in using symptom control measures (e.g. medications, advice and psychotherapy).

*Patient III* immediately started by talking about her experience with her cancer during the first session, saying:

*“I was so anxious when I heard that I had breast cancer and I feel so depressed at the moment.”*

She said that she needed somebody to talk to but she and her husband was not on good terms with each other during the time of her diagnosis and neither was she and the children. I gave her the opportunity to voice her emotions concerning the relationship with her daughter and the hardship that it was causing her. She talked freely about her marriage and the lack of emotional support from her husband and talked at length about their financial worries. I explained to her that by talking about something that is pressing on you for a long time can be a healing experience in itself (the patient said that she was not somebody who spoke easily about how she felt). She said she was very glad to be able to talk about her feelings regarding the cancer and also her other personal issues. Although the expression of negative emotions had long been considered important for psychological wellbeing, some cancer patients are scared that feeling ‘too deep’ and sharing their deepest emotional experiences might lead to weakness and self-pity and that other people might look at them in that light (Lieberman & Goldstein, 2006; Linstrom et al., 2010). The patient was encouraged to talk about her past, especially her relationship with her daughter because by not dealing with it, it could prevent her from dealing effectively with her cancer. I explained the importance of talking about her emotions and to acknowledge it and that although

she can deal with her “old” issues and emotions now, she should also focus on the cancer and current emotions and needs regarding that. She said:

*“The only place that I can talk about my emotions is during our sessions.”*

I noticed during our sessions that the patients found it hard, for various reasons, to speak to their oncologists about their personal experiences and emotions. Studies have documented that oncologists, like other medical providers, often do not respond empathically or even recognised patient distress even when it is expressed (Dean & Street, 2014; Fallowfield et al., 2001; Merckaert, Libert, & Razavi, 2005; Zimmerman et al., 2007).

To summarise emotional catharsis, Dean and Street (2014) confirmed in their three stage model that acknowledgement and exploring emotions have some therapeutic value for the cancer patient. This lessens emotional suffering and responding empathetically to negative emotions in therapy can reduce a patient’s distress and improve their quality of life. This was also supported by Zachariae and co-workers (2003) and Barak and colleagues (2008).



**Figure 7.1: The three stage model of recognition and exploration of emotions (Dean & Street, 2014).**

#### **7.4.1.2 PSYCHO-EDUCATION**

Lim and colleagues (2011) specified that in practise the first step before using psycho-education as an intervention technique is to give the patient enough time to talk about her cancer experience and to give her a chance to clarify what she understood about her disease and treatment. This is also the time for the patient to express her emotions regarding her cancer experience (as discussed in emotional catharsis) to determine what her needs are in terms of the forward therapeutic process. Psycho-education, in combination with emotional expression and support and cognitive-behavioural therapy, is one of the most frequently used psychotherapeutic interventions in treating breast cancer patients through



teaching them about their cancer and cancer treatment (Donker, 2009; Fors et al., 2010; Spiegel & Rodrigues, 2008).

As psycho-therapist I put high value on psycho-education in combination with emotional expression and CBT as a therapeutic intervention tool working with breast cancer patients and am a sturdy supporter of the concept of 'knowledge gives power'. Barak and colleagues (2008) voiced this theorem by saying that a sense of personal empowerment can be achieved by the cancer patient through acquiring cancer related information and knowledge through their oncology team, which will give them a better understanding of what they are facing and more knowledge of how to handle it.

**Theme 12: “The power of knowledge”- normalizing and explaining breast cancer treatment related phenomena:**

In practice, psycho-education means giving information to the breast cancer patient about her disease and treatment (Donker, 2009; Fors et al., 2010; Spiegel & Rodrigues, 2008), which will enable her to become involved in making active choices in her treatment process and to understand her own experiences better (Barak et al., 2008). Giving your patient adequate information in their present situation, can give her a sense of control over her situation and will allow her to process the cancer in a less negative way and avoid dwelling on problems that might arise (Loiselle et al., 2006; Rees & Bath, 2000). Greeff (2008) and Dorrepaal and colleagues (2012) state very clearly that an informed cancer patient is able to ask relevant questions concerning her illness and treatment, not just to make certain treatment decisions, but also in attaining a sense of cognitive mastery and control.

The mere knowledge that a percentage of all breast cancer patients will develop depression and/or anxiety during their cancer journey can bring a certain amount of relief to the patient when experiencing these conditions (Brem & Kumar, 2011; Spiegel & Rodrigues, 2008). By acknowledging a patient's fears and anxiety and explaining the “normality” of these emotions during the cancer journey, can make the patient feel less threatened by her anxious and depressive thoughts and contribute to her feeling validated by being told that their emotional reactions were normal in her specific situation. Normalization of negative emotions and thoughts

are seen as a benefit in its own right and as a therapist, I support this concept and make use of it continuously during the therapeutic process when working with breast cancer patients (Nekolaichuk et al., 2012).

I experienced that both *Patients II and III* benefitted a lot from psycho-education by step-by-step learning about their cancer treatment and their emotional and biological experiences. I had the opportunity to explain to them what they could expect of their chemotherapy and all the relevant side-effects as they went along, for instance the difference between the “Red Devil” and Taxol, the two types of chemo that they received and their different side-effects. They were given enough time during their sessions to express their emotions regarding their experience of the chemo first, and then they were provided with relevant information of their present experiences and questions. This is one of the aims of psycho-education, to be able to give the patient a sense of cognitive mastery by explaining their symptoms (Dorrepaal et al, 2012). Both of them confirmed after every session that they understood what was happening to them physically and biologically and were able to put their current and active chemo-related symptoms immediately in the cancer treatment framework with plans of how to accommodate it. By explaining the side-effects of the chemotherapy through psycho-education, (as they experienced it) prepared them for the treatment and prevent unnecessary anxiety and gave them a better understanding of what they were facing with more knowledge of how to handle it (Barak et al., 2008; Jacobsen & Jim, 2008; McQuellon & Danhauer et al., 2006; Vahdaninia et al., 2010).

*Patient II* experienced severe tiredness as the chemotherapy went on that caused her a lot of anxiety and she strongly felt that the tiredness affected her emotional wellbeing and level of functioning and was the main topic of our sessions during the chemotherapy. The aim of psycho-education in combination with behavioural techniques with acute fatigue is to prepare the breast cancer patient with knowledge about her current fatigue and its interference with function and possible handling mechanisms. It was explained to her that chemo-related fatigue is a very common and prominent side-effect of chemotherapy and that it can be relentless and persistent and can make physical action difficult and slow, hence her struggle to do her house chores. Literature highlighted the notion that fatigue can be

particularly acute in the first few months after diagnosis and can affect the patients' life through changes in her ability to function on daily activities such as work and relationships (Fernando, 2001; Johns et al., 2015; Sohl et al., 2014). I explained to her the importance of understanding her own unique pattern of tiredness, e.g. which day after chemo was she most tired and what time during the day was the worst. Through explaining chemo-related fatigue, I tried to put the patient's experience of tiredness in context with her treatment and to normalize her feelings around it and the importance of accepting the tiredness as a passing element in her life, related to the treatment. I explained some practical ideas regarding her tiredness, for example that she can time manage her day around the fatigue and also involve her family into her "fatigue-schedule" (Bardwell, & Ancoli-Israel, 2008). Examples are to rest on the bed with a book or watching TV without feeling guilty or thinking that she is lazy, but rather as a way of dealing effectively with her situation. In answer to that she said:

*"I can take up knitting again, it is passive, so I can rest while doing it. ...I am already looking forward to it."*

Another practical alternative that was discussed was to hire help once a week to release her from some of the household chores which made a lot of sense to her, she said:

*"I have never thought about it before and will discuss it with my husband."*

It was explained to her that she could still do some of her house- and garden work, but at a different pace as before the cancer. She could develop a new way of doing her every day chores and if she changed her behaviour to rest more and conserve her energy, she could use it for more important activities like looking after herself, doing relaxing activities and spending quality time with her husband and children. We also discussed prioritising her activities, for instance she had to decide which activities were the most important in terms of quality of her life and do that first when her energy levels were higher and leave the rest either for somebody else, or do it when she felt less tired. As per definition, psycho-education can be defined as a therapeutic focus in which patients can learn practical and positive emotional and behavioural skills through information and

knowledge to improve life adjustments (Authier, 1977; Berger et al., 2015; Fors et al., 2010). The patient said after talking about her tiredness:

*“...the information that you gave me about the side-effects makes it less unfamiliar and scary and worrying. ...I understand it better.”*

By providing the breast cancer patient with knowledge about treatment related symptoms and the impact of fatigue, the development of serious psychiatric problems can be prevented and it is confirmed in the literature (Jenkins, 2015; Greeff, 2008; Husson et al., 2011).

With the second round of chemotherapy, *Patient II* experienced pain as a side-effect and because she was unprepared for it, it was a shock to her and it made her anxious and scared, she said:

*“...I did not know what was happening to my body.”*

We discussed that pain correlates positively with negative emotions such as anxiety and depression (Rainville, Bao, & Chrétien, 2005) and that pain can be a prominent side-effect of chemotherapy and often co-occurs with cancer-related fatigue (Brem & Kumar, 2011; Lueboonthavatchai, 2007; Vahdaninia et al., 2010; Wong-Kim and Bloom, 2005). It was pointed out that she must talk to her oncologist about her pain and her experience of the pain so that he could help her manage it through pain medication (Breivik et al., 2009).

*Patient III* experienced both types of chemotherapy very negatively, especially the alopecia and nausea. I explained to her that the nickname of the chemotherapy ‘Red Devil’ originated from the beetroot extract which is an ingredient of the chemo which is called Doxorubicin or Dox for short, hence the red colour and that some of the well-known side-effects are nausea and vomiting, complete alopecia and that urine, tears and sweat can turn pinkish red (Kapadia, Azuine, Subba Rao, Arai, Akira, & Harunkuni, 2011; Opperman, 2015).

This patient experienced the same trauma as Patient II in terms of her second type of chemo as she was also not prepared for the vicious side-effects that she experienced. After giving the patient time to express her emotional experience of

the side-effects of the chemotherapy, I explained that the following Taxol side-effects are common and that she could experience some of it; an increased risk for infection, hair loss, pain in the joints and muscles, numbness and tingling of the hands and feet, nausea and vomiting (usually mild) diarrhoea and mouth sores (<http://www.breastcancer.org/treatment/druglist/taxol>). This patient also experienced tiredness from the beginning saying:

*“...the tiredness is the worst; it is very bad and starts the same day of the chemo.”*

We discussed that fatigue is a very common and prominent side-effect of chemo therapy and that it can be very unpleasant and persistent and that she has to work around her own unique pattern of fatigue by accepting it and making provision for it and to make sure that she rests enough every day. This is supported in literature highlighting the notion that fatigue can be particularly acute in the first few months after diagnosis and during treatment and can affect the patients' life through changes in her ability to function with daily activities such as work and relationships (Fernando, 2001; Johns et al., 2015; Sohl et al., 2014). The patient talked about still doing her house chores, but that her husband was helping her out with that and that it made a difference for her because then she could rest more.

Patients II and III received their confirmed dates of their breast surgery during their last chemo session and both experienced high levels of fear and anxiety regarding the scheduled dates and procedures. They both said that they do not even feel like celebrating the end of their chemotherapy. I have explained to them that every treatment process (chemotherapy, radiation and surgery) generates its own fears and expectations and emotional- and physical outcomes and that every time that they start with a new treatment there will be new fears and uncertainties, as it is now with the surgery. Aviado-Langer (2014) emphasises that the pre-operative stage can be dominated by stressors such as waiting for the surgery and the pathology results and fear of the disease and the stage of disease, which all cause anticipation anxiety and uncertainty. The aim of the therapy here was to handle their acute fears and anxiety of the surgery first through emotional support and then the application of psycho-education to explain the procedures to follow, normalising and accepting of the stressful emotions and relaxation and breathing

exercises (Golden-Kreutz et al., 2005; Mulan, 1985; Hulbert-Williams, et al., 2011). It was also explained to them what anticipation anxiety is and that although this anxiety is for something that must still happen, it is still very real and draining, but also very natural (Berger et al., 2015; Lim et al., 2011). It was explained to them during therapy that when they were so anxious they should make a conscious effort to relax by doing relaxation and breathing exercises. I explained in full how deep breathing and muscle relaxation works. I told them to think about things that can relax them, or to get involved in activities like taking a walk with their husbands to divert their minds from extreme stressful thoughts. This was supported in literature that recommended psycho-education in combination with any form of behavioural psychotherapy in preparing patients for cancer treatment (Jacobsen & Jim, 2008; McQuellon & Danhauer, 2006; Vahdaninia et al., 2010).

*Patient III* was also anxious about leaving her husband behind when she went to the hospital and the therapeutic input here was to explain that every situation had a practical and a bio-psychological side to attend to. The case with her husband was more on the practical side and therefore easier to manage and make plans for. The alternatives that were looked at were for example, her grown-up children or other family members could help him with tasks that he could not physically manage on his own. She could prepare and refrigerate his food in advance for the time that she would be in hospital and he could just warm it up in the evenings. She could also ask him what his expectations were for the period that she was in the hospital and they could both make plans for him to cope. The message here was, instead of just worrying about something, she could learn to look at it from different angles and make plans to either solve the problem or to make it more manageable. I experienced the patient more at peace with herself and relaxed about the situation at home after discussing the alternative plans for the surgery.

On the day before the surgery, I gave the patient time to talk about her feelings regarding the surgery and although she was more at peace with the surgery she said:

*“...It is going to happen at last...”*

She was also worried about her heart, she explained that the anaesthetist had detected a heart murmur and according to him, most probably related to the chemo, she had never previously had a heart problem. During the session we reinforced the normality of feeling anxious before surgery and instead of fighting the emotion, she should rather acknowledge and accommodate it. She was advised to focus on her breathing and relaxation during the day and to divert her focus on something else like going somewhere with her husband or participating in any activity that will take her focus away from thinking about the operation the whole time. At the end of the session she said:

*“I already feel better for talking to you and I will do something with my husband today not to think about tomorrow.”*

She also gave feedback from the previous session saying that she had prepared everything at home for him (as we have discussed) for the days that she would be in hospital saying:

*“...you know it makes me feel less guilty for going away and leaving him alone.”*

The patient said that the oncologist had explained that she would undergo radiation therapy after the surgery and she asked a lot of questions about how it worked. Her main concern regarding the radiation was whether her husband would be affected by the radiation rays and if she would be allowed to sleep next to him at night. I encouraged her to talk to her oncologist and to ask all her questions at her next appointment. I told her that she should not be afraid or ashamed to ask questions and that she would feel more in control if she knew what to expect. According to literature, inadequate communication causes distress for cancer patients. They often feel that they would like to have more information regarding their illness and treatment. More than what is provided and that giving information would give them a better understanding of what they are facing and more knowledge of how to handle it (Barak et al., 2008; Fallowfield & Jenkins, 2015).

After the surgery, the patient also complained about experiencing pain in her arm and she was waiting for an appointment with the oncologist to ask about the pain

and for treatment of it. I explained what lymphedema is and what she can expect of that.

*Patient 1*, who had been finished with her treatment for 15 months, said during the first session, that if she had the relevant knowledge about the cancer treatment and what she was going through it would have helped her to have been more prepared and equipped for the different stages of treatment. She said that the different emotions that she went through and didn't understand, was never explained to her. This lack of information that the patient experienced was supported by Surbone and colleagues (2013) saying that therapists working with cancer patients need to explain the unpredictable and uncertain nature of breast cancer and its consequent existential uncertainty so that they can understand the picture of cancer and what they might expect of their cancer journey. The patient said:

*"...to me, cancer was such a new and completely unfamiliar situation. You need to learn new skills from somebody who has the necessary knowledge and know-how of how to handle yourself and your family and the situation."*

This feedback from the patient confirmed the importance of psycho-education from the beginning of the cancer diagnosis. Psycho-education should provide information regarding specific areas that will give the patient a better understanding of what she is facing and prepare her for the treatment (Barak et al., 2008; Jacobson & Jim, 2008; Vahdaninia et al., 2010). She said she experienced that her fear and anxiety was worse after the end of the treatment when she thought that everything was supposed to be "back to normal." I explained the pathogenesis of anxiety and depression in the context of cancer and the chemical impact it can have on the brain and body and the discomfort it can cause when left unattended. We discussed the importance of acknowledging and allowing herself to feel anxious without feeling guilty and to understand that cancer related anxiety and fear are not unrealistic, but in par with what literature says that a confrontation with a person's own mortality can and most probably will cause acute psychological stress (Brem & Kumar, 2011; Spiegel & Rodrigues, 2008). Anticipation fear for follow-up examinations and their results and the uncertainty of the future in terms of recurrence, which is a reality in the post-cancer status quo,



was also discussed with the patient (Berger et al., 2015; Travado & Reis, 2013; 2013; Vahdaninia et al., 2010). It was explained to her that a substantial number of breast cancer patients in their remission phase report a late increase in distress and psychological suffering, even developing depression and/or anxiety. She understood that this occurrence is not an abnormal phenomenon and also fits in with her current experience and her presenting with a major depression and anxiety, (American Cancer Society, 2010; Brem & Kumar, 2011; Henselmans et al., 2010; Hopko et al., 2016). Ganz and co-workers (2004) explained that they found that patients are often astonished and disappointed in themselves for experiencing chemotherapy-related- and mood problems months after ending their treatment. The patient understood that a pre-morbid psychiatric history such as hers was a well-known risk factor in developing depression and/or anxiety during and after breast cancer and cancer treatment (Hill et al., 2010). Through psycho-education the therapist had tried to put the patient's experiences throughout her cancer treatment in perspective by explaining that there are a number of challenges during the period of diagnosis and the process of active treatment like treatment side-effects such as fatigue, pain, depression and insomnia which can be particularly acute in the first few months after the cancer diagnosis. She also understood that this can affect a cancer patient's life through changes in her ability to function in daily activities such as work and family- and social functioning, where she experienced a lot of changes and difficulties (Sohl et al., 2014). The patient voiced her guilt feelings regarding her absence in her children's day to day functioning while she received her treatment. It was explained to her that women with younger children with their accompanied demands and responsibilities, and with the extra time and energy it requires together with a busy cancer treatment schedule, tend to experience more psychological distress after the diagnosis of breast cancer (Lebel et al., 2013; Wong-Kim & Bloom, 2005). The patient understood that it was not abnormal to want to minimize disruption to her family life, to be strong for them and spend as much time as possible with them in order to still feel like a 'good' parent (Bilhult & Segesten, 2003; Simple & McCance, 2010; Walsh & Avis, 2005). Therapists working with cancer need to understand that parents with cancer need support and guidance about how best to manage their family life during the acute treatment stage and address issues and challenges as a parent surviving cancer (Semple & McCance, 2010). Breast

cancer patients often struggle between being a good parent and to care for their children and their own need for care, especially during the acute phase of treatment and treatment side-effects (Semple & McCance, 2010), therapists needs to put this in perspective for them and provide them with knowledge on how to handle children of different ages and to enhance open communication about the cancer and carrying on with their functioning as a family.

*Patient IV* had a very long history of depression and said that she tends to become easily depressed and anxious and noticed that while she was undergoing her treatment, especially chemotherapy, her symptoms of depression increased. The therapist explained to her that risk factors for depression during breast cancer can be due to the cancer or cancer treatment, but can also be related to her personality and relevant psychodynamics (Burgess et al., 2005; Reich et al., 2007). A pre-morbid psychiatric history, as is the case with her, is also a well-known risk factor in developing depression during and after breast cancer and cancer treatment Hill and co-workers (2010). In the framework of an existing propensity of developing depression, it was explained to her that there are a number of challenges to endure during the period of diagnosis and the process of active treatment, including treatment side-effects such as fatigue and pain, mood disorder and insomnia, all of which she experienced and didn't know how to handle at the time (American Cancer Society, 2010; Brem & Kumar, 2011; Henselmans et al., 2010; Hopko et al., 2016). She answered by saying that:

*“I think that I would have been able to control my emotions better if I could have spoken to somebody regarding the cancer and my fear of developing depression again.”*

The fact that she realised that there was an increased possibility that she could develop depression and that she had phoned her psychiatrist to make an appointment to sort out her medication, showed me that she was capable of taking ownership and responsibility for her healing process. Although she would have liked to see a psychologist during her treatment, I told her that it was not too late now and that she could still learn new skills to handle herself and her “new” situation.

Because the patient's depression had escalated throughout the first couple of sessions, I made use of psycho-education, constantly explaining her symptoms and experiences to her. This dealt with both her major depression and the side-effects of the chemotherapy. I also explained that these 'double' symptoms could be quite overwhelming and that suicidal thoughts could also be present. I told her that we must be aware of it and deal with it if it exists. I explained to her that if she felt that she cannot cope anymore there are other alternatives when managing depression, for instance admittance to a hospital or clinic catering for mood disorders, changing her medication by the psychiatrist or increase the therapeutic sessions.

*Patient V* only presented with symptoms of depression after she was finished with her treatment. Because she experienced such bad side-effects from the chemotherapy (especially the "Red Devil") and the fact that she still experiences vivid pictures in her head, reliving the experiences often, and the influence that it has on her marriage and overall functioning, I used psycho-education to explain to her why she was experiencing acute emotional and biological symptoms after the end of her treatment.

Therapists must understand that most people are unfamiliar with conditions like depression and anxiety and by explaining the different degrees of distress experienced at different times during their cancer journey, can give the patient the freedom and surety to concentrate on their cancer treatment and recovery instead of worrying over unfamiliar symptoms that they don't understand (Berger et al., 2015; Lim et al., 2011).

It was explained to her what impact treatment side-effects such as nausea, vomiting, fatigue, depression and insomnia can have on a person's functioning even after the treatment and especially on activities such as work and relationships (Sohl et al., 2014). She could relate to this information because she felt depressed about her losses and marital problems but admitted that she was not familiar with how depression works or why she suffered from it. The patient never had any assistance in receiving knowledge regarding the biological or emotional side-effects on her functioning during her treatment or the period after that.

She said it worried her that her energy levels were still very low and that she had problems with her short term memory and ability to concentrate. It was important that she realised that some symptoms could carry on for some time after treatment in different degrees, as in mood disorders and fatigue and by handling it effectively through skills she could prevent the development of serious psychiatric problems (Benjamin, 1995; Fallowfield & Jenkins, 2015; Greeff, 2008; Husson et al., 2011). I also emphasized that she should give herself time to heal and get back to a level of functioning that she would be satisfied with, but in the mean time she could use techniques to make life easier for her, (with her incapacitations) e.g. to work around her fatigue by taking more breaks to help with her concentration and to rest more. She could reserve her energy through prioritising her tasks, involving other people to help with certain chores and to do light exercises (Bardwell, & Ancoli-Israel, 2008). She can also communicate with her colleagues about her work load and her ability to do her work and accept their support.

In terms of her functioning with her child, where she still had a lot of guilt feelings, she should allow herself to look back at the time of treatment and 'see' that she was still involved in his life during that difficult period, even if it was more passive than before the cancer and allow herself to work through those emotions. Practical changes with her child that she could implement were to 'play' with him without getting too tired, for example, instead of running around and playing with a ball, they could participate more in passive games like colouring in, playing hide-and-seek in the house and reading or watching TV together. Because it was so important for her to be involved in her child's life she could, by altering her actions and time with him in a more suitable way for her, prevent her from feeling guilty of not spending enough quality time with him. Literature support the struggle that young mothers have regarding their cancer treatment and fulfilling their role as mothers and the importance of guidance from professionals especially to understand and handle their feelings of guilt about not being a good parent (Semple & McCance, 2010). I explained to her that when someone is diagnosed with cancer it creates several problems for the family which add to the normal day to day challenges of family life. It can be a difficult time for parents while they have to cope with a troublesome diagnosis and subsequent treatments, but also continuing to meet the needs of their children, or child as in her case (Semple &

McCance, 2010). We also talked about the importance of understanding that her role as mother was compromised because of the cancer, but it did not mean she was any less of a mother because of the cancer. Having a young child can make the cancer experience worse and can be a further stressor for a mother because of the energy and time going into being a caregiver (Lebel et al., Wong-Kim & Bloom, 2005) and the fear of leaving a young child behind if you die. The mere confrontation with your own mortality can also cause acute psychological stress (Brem & Kumar, 2011; Spiegel & Rodrigues, 2008).

It was explained to her that it would help to accept the fact that there will be a difference between how she was before the cancer and her functioning then. That the way she was as a person, wife and mother before the cancer did not exist anymore and that there was a 'new' person, wife and mother at the other side of cancer, but that it is not necessarily a negative concept, just different, asking for new skills and adaptation (Baider et al., 2000; Surbone et al., 2010).

It was explained to patients I, IV and V who all three suffered from depression and anxiety after the completion of their treatments (as long as two years after diagnosis) that distress in the re-entry phase might be a delayed psychological response to the chaotic and frenetic period of diagnosis and treatment. It was further explained that once in a calmer period the cancer experience might finally start to sink in causing a delayed or belated increase in distress or even a diagnosis of depression or anxiety (Henselmans et al., 2010). To normalize this specific phenomenon seemed to me as a therapist, as one of the most adequate and able interventions helping the breast cancer survivor to cope with the re-entry phase of breast cancer (Ranchor, Wardle, Steptoe, Henselmans, Ormel, & Sanderman, 2010).

- **Changing from 'cancer patient' to a 'post cancer status quo' and coping with permanent changes and the chronicity of breast cancer**

The re-entry- or survival phase brings its own particular challenges for the breast cancer patient and there is evidence from recent studies that there are prominent problems related with the transition from being a cancer patient to being a cancer survivor (Dolbeault et al., 2009; Henselmans et al., 2010; Stanton et al., 2005).

This difficult transition is often the result of a lack of effective preparation for the re-entry phase by the health care professionals, leaving the cancer survivors in a stage of 'limbo', uninformed and underprepared (Stanton, 2012). Cook and colleagues (2015) feel that all cancer patients will benefit to undergo regular psychological assessment from diagnosis throughout the treatment process and into survivorship and to have access to psychological support to assist them not just during the treatment period, but also into survivorship. It will be valuable for the breast cancer survivor to have knowledge and insight in the fact that at the end of their treatment and at the beginning of their survivorship, celebration and fear and anticipation anxiety and even depression can all co-exist. Reasons for this challenging opposite emotions can be the sudden end of the visits to the oncologist and other clinical specialists, leaving the patient without her medical support system. There exist also the continuous fear and anxiety that relates with future concerns such as treatment outcomes, recurrence of the cancer and the threat of death (Ganz et al., 2004; Golden-Kreutz et al., 2005; Kyranou et al., 2014; Lebel et al., 2013; Stanton, 2012).

*Patient II and III* were nearly finished with their radiotherapy (the last of the treatments) when we terminated our sessions and we discussed the fact that breast cancer is a chronic illness and that there will be a bridging time to go from breast cancer patient to a 'normal' person again and that it might take some time for them to get used to their 'new' status quo as a breast cancer survivor. I explained that they can never be the same again as before the cancer experience and that they will feel and think differently now and that even as part of a couple they will look differently at each other and life. This explanation is supported in the literature where authors such as Baider and colleagues (2000) and Surbone and colleagues (2010) said that the breast cancer patient and her family will benefit from knowledge that they can never return to their pre-illness status quo and that the only way to reach a successful overall functioning is through proper education about both the short-term and long-term impact of their illness. It was emphasised that these changes are not necessarily all negative but can all be part of personal growth. I have explained to them that although they are still busy with their treatment, it will be good for them to understand that there will also be a process to go through once they were finished with their treatment and in the next stage of

their cancer journey. This next stage is also known as the re-entry phase and that because the rush of the acute and very busy treatment are then over and it is a calmer period, the cancer experience might only start to sink in then and can cause a delayed shock reaction (Henselmans et al., 2010). I explained that this reaction(s) are not abnormal but they will be able to recognise it with the advantage of their therapeutic sessions and either use their new skills to handle and accommodate it, or they could seek help from a professional person. I also prepared them for a possibility that they might find a heightened need for continued interpersonal support after the treatment and perhaps find it unavailable (especially people outside the family circle), because family members and friends often expect that, after completion of the cancer treatment, the woman will be able to recommence all of her usual activities and responsibilities at her pre-cancer level of functioning, (Ganz et al., 2004; Stanton, 2012; Wurtzen, 2013).

*Patient I said:*

*“...I have never thought about cancer or my cancer as a chronic disease...”*

I explained to her that post treatment cancer survivors often experience remaining and sometimes even lasting physical and psychological consequences of the treatment and may realise only then for the first time the chronicity of cancer, even, as in her case, when treatment was declared successful (Ganz et al., 2004; Haber et al., 1995). We discussed the concept of chronicity in terms of a lifelong process of going for follow up sessions to her oncologist and waiting for test results accompanied with anticipation anxiety. We also discussed living with treatment side-effects such as a diminished memory and tiredness and a changed body and sexuality that are all daily reminders of her cancer. She understood that through relevant information and knowledge and learning new skills in terms of her thought processes and behaviour and to adapt and make peace with her new status quo she will be able to function on a high but different level again with a chronic disease such as breast cancer. The patient said:

*“...because I was so anxious and depressed at the end of my treatment, I have decided to go to a psychologist for therapy.”*

I could give her reassurance that to many breast cancer patients, depression and anxiety can develop or become more serious after treatment or when already in remission which are supported from the literature saying that breast cancer survivors often report that they were unprepared for the complex rehabilitation process and persistent symptoms of depression or anxiety after the end of their treatment (Brem & Kumar, 2011; Burgess, et al., 2005; Dolbeault et al., 2009; Reyes-Gibby et al., 2012). The patient received this information very positively.

Both *Patient IV* and *Patient V* experienced difficulties to adapt in 'real life' again after their cancer journey. They experienced high levels of anticipation anxiety for their follow up sessions with their oncologists and waiting for their results. *Patient V* also experienced fear of recurrence of her illness and dying. Because of this, I have explained again what anticipation anxiety is and that it will be part of the chronicity of her illness and something that will need to be dealt with every time it surfaces (Berger et al., 2015; Lim et al., 2011). The role of emotional regulation in the process of adjustment to chronic illness where they will keep on acknowledging and dealing with their negative emotions surrounding chronic occurrences of their breast cancer (de Ridder et al., 2009) was explained to *Patients IV and V*. Both of them, only realised then, after the completion of their treatment, the chronicity of their cancer, even in the face of successful treatment and remission (Ganz et al., 2004; Haber et al., 1995). They understood through the therapeutic sessions that returning from a 'cancer patient' back to a 'normal person' will take some effort and time (Dolbeault, et al., 2009; Henselmans et al., 2010; Stanton et al., 2005). *Patients I, IV and V* were unprepared for the rehabilitation process and persistent symptoms of their depression and anxiety after the end of their treatment and were very thankful and ready to have received knowledge about this status quo and skills to handle it (Brem & Kumar, 2011; Burgess et al., 2005; Dolbeault et al., 2009; Reyes-Gibby et al., 2012).

It was explained to the patients that although the end of their cancer treatment is a time for celebration, which it is, it is also a phase full of its own distresses and challenges. I explained that the most mentioned problems during this phase could be the lingering adverse physical and emotional side-effects of the cancer treatments such as loss of physical stamina and fatigue, sleep disturbance,



cognitive problems and menopausal symptoms and worries about the risk and fear of recurrence, changing of psychosocial needs and the uncertainty of the future (American Cancer Society, 2010; Burgess et al., 2005; Dolbeault, et al, 2008; Ganz et al., 2004; Golden-Kreutz et al., 2005; Haber et al., 1995; Henselmans et al., 2010). Therefore the importance and aim of psycho-education in this stage is to clarify all of these symptoms and experiences for the cancer survivor (Greeff, 2008; Hopko et al., 2008; Hulbert-Williams et al., 2011; McQuellon & Danhauer, 2006).

#### **7.4.1.3 COGNITIVE AND BEHAVIOURAL THERAPEUTIC TECHNIQUES**

Cognitive and behavioural therapy with all its different components such as emotional expression, structured psycho-education, cognitive restructuring and behavioural activation have been shown to be effective for breast cancer patients because of their practical and applicable methods, it can be short-termed and is easily understood by most people (Armento et al., 2008; Carver, 2005; McQuellon & Danhauer, 2006; Hopko et al., 2008; Savard et al., 2005; Spiegel & Rodrigues, 2008). Cognitive and behavioural techniques were the therapeutic preference of this study.

#### **Theme 13: The acceptance and adaptation process:**

Loss and grieve are experienced by many breast cancer patients as they cope with the shock of their diagnosis, deal with the side-effects of the cancer treatment and continuously battle with an unpredictable and uncertain future and even possible death. Dealing with multiple losses can be a very prominent task faced by a person with a life threatening illness such as cancer (Kissane et al., 1997; Tacón, 2011; Mystakidou et al., 2008; van Heeringen et al., 1989). The aim of the therapeutic process here will then be to facilitate the patient's grieving process by firstly acknowledging her losses and the seriousness of her situation within a safe and non-judgmental context and secondly to explain what a grieving process entails (Kübler-Ross, Kessler, & Shriver, 2014; Lee, 2008). I want to clarify here that I have not used the traditional grieving process of Kübler-Ross during therapeutic interventions, but has rather used emotional expression and acknowledgement of emotions, which were put in the framework of losses. In facilitating acceptance, it must be seen as part of an active grieving process (or

working through emotions). Successful acceptance and adaptation in the cancer framework will be reflected in the cancer patient's capability to re-establish and manage her external environment and inner cognitions, feelings and behaviours (Kübler-Ross et al., 2014; Livneh, 2001). Successful adaptation is considered to be on-going and dynamic throughout cancer survivorship with cognitive restructuring of goals as the main mechanism of change (Brennan, 2001; Livneh, 2001; Naus et al., 2009).

*Patient I* explained that her biggest losses were her permanent adaptation to the chronicity of her illness, her hormonal changes, menopause, and body image and changed sexual functioning. The therapist emphasized here the permanent changes that breast cancer can cause but that she could adapt to these changes through conscious efforts to work through and acknowledge her losses and emotions and to learn new coping mechanisms for a new chronic situation. Literature explained this by saying that in the absence of awareness of the grieving process, it might end up being repressed which can affect adjustment to the illness and survivorship (Sarenmalm et al., 2009; Tacón, 2011). The patient said that:

*"...although I am in remission I have never allowed myself to work through any losses."*

I explained to her that to work through losses, the losses must first be acknowledged by her and then working through the accompanied emotions (emotional expression) before she can let go of the loss or losses to get to the acceptance phase and making peace with it. The patient said her biggest challenge was to come to terms with the reality that there is no answer or explanation for her breast cancer and that she has to accept it and make peace with it, although she will never understand it or find an answer. Lee (2008) supported this by saying that cancer patients struggle with their illness because of the multitude and distressful present and future losses and changes and uncertainties and through letting go of their losses, they could ease their distress.

She also experienced the changes that she had gone through, regarding her work, as a big loss. She had decided to scale down a lot on her working hours and

stress related elements and incorporate more time for activities that was more relaxing and beneficial for her health and relaxation. She was also more mindful of situations that created stress and affected her mind and body and to either avoid it or handle it effectively. It was explained to her that accepting and adapting to a chronic illness is a long term process which takes time and skills to achieve. This was supported by Livneh (2001) stating that adaptation refers to the psychological processes that occur over time as the patient learns to cope, learn from and adapt to the multitude of changes which has been generated by the illness and its treatment.

*Patient IV* explained that one of her biggest challenges was that of her constant lack of energy and short-term memory and the influence it had on her work. I emphasized that by putting too much pressure on herself to do her work perfectly all the time can also contribute to her depression and difficulty in adaptation to her slower functioning. To be able to adapt to her fatigue, she could learn to prioritise her activities and make use of practical behavioural techniques such as taking of time every day, even at work, to take a proper brake and rest so that she could preserve her energy to do things that she enjoyed and make her feel better and more positive which then will contribute to her quality of life (Nusbaum et al., 2003). Because every patient experiences fatigue differently recommendations for fatigue self-management will be personalized for suiting the patients unique personality, age, work- and social circumstances (Bardwell, & Ancoli-Israel, 2008; Berger et al., 2015). Because the patient was so emotional during the sessions (especially the first three) I have validated the importance for her to acknowledge her emotions and talk or write about it and to consciously engage in a grieving process or emotional exploration to mourn all her losses. It was explained to her that the cancer experience, losses and new adaptations are often only a reality after the cancer treatment and need to be recognised and worked through. We talked about facing her emotions regarding the loss of her breast and she said that she knew that she needed to face it in a proper way through talking about it and accepting it. Adaptation and subsequent coping are not static and can change during the course of the cancer treatment and therefore the oncology team must be aware of this and re-assess the cancer survivor for psychological distress over time (Naus et al., Little et al., 2002).

*Patient V* had continuous problems with lack of energy and short term memory which had incapacitated her general functioning and also her work functioning and caused a lot of anxiety and feelings of depression and uncertainty. Work was an important part of her life and she kept on comparing her work functioning then with how she had performed before the cancer. I again explained the principle of changing from 'before' the cancer to 'after' the cancer and that to be able to adapt to her next level of functioning within in the cancer framework it was important for her to accept the fact that there would be a difference between how she was before the cancer treatment and her functioning then. I have attempted to ease her negative feelings and reassured her that her fears and emotions regarding her changes and losses were justifiable in order to help her to let go of her losses and adapt to her new reality (Lee, 2008). The patient understood that, because of all her losses and multiple changes she went through, she could not be the same person again as before the cancer and could not look at life or herself as before the cancer (Baider et al., 2000; Surbone et al., 2010). It was also explained to her that some of her symptoms were acute and short-term and needed only short-term adaptation (e.g. tiredness and short-term memory) and that some symptoms were more permanent and needed permanent acceptance and adaptation (e.g. certain thought processes, menopause and hormonal changes). The feedback from the patient was that she understood that her level of functioning concerning her work (memory and energy) was only temporary, saying:

*"...it makes it less scary for me knowing this."*

Another therapeutic aim was to talk about acceptance of life-long follow ups which was quite a stressor for the patient because of her fear for recurrence. I aimed to explain that the anxiousness that was linked with 'for ever' follow ups and tests and waiting for test results were 'normal' anxiety and by adapting to it she could learn to work with the anxiety instead of against it by allowing herself to be open to anxious thoughts and talk about how she felt. The acceptance and commitment therapy model actually encourage cancer patients to be open to whatever one is experiencing without resistance and to accept negative thoughts and feelings such as guilt and anxiety and that acceptance can be an important alternative to avoidance (Hayes et al. 2006; Hofmann et al., 2010; Masuda, 2008; Wetherell et

al., 2011). Fears and uncertainty about the illness and the future specifically, when not managed effectively, can affect the adjustment to the (chronic) illness (Sarenmalm et al., 2009).

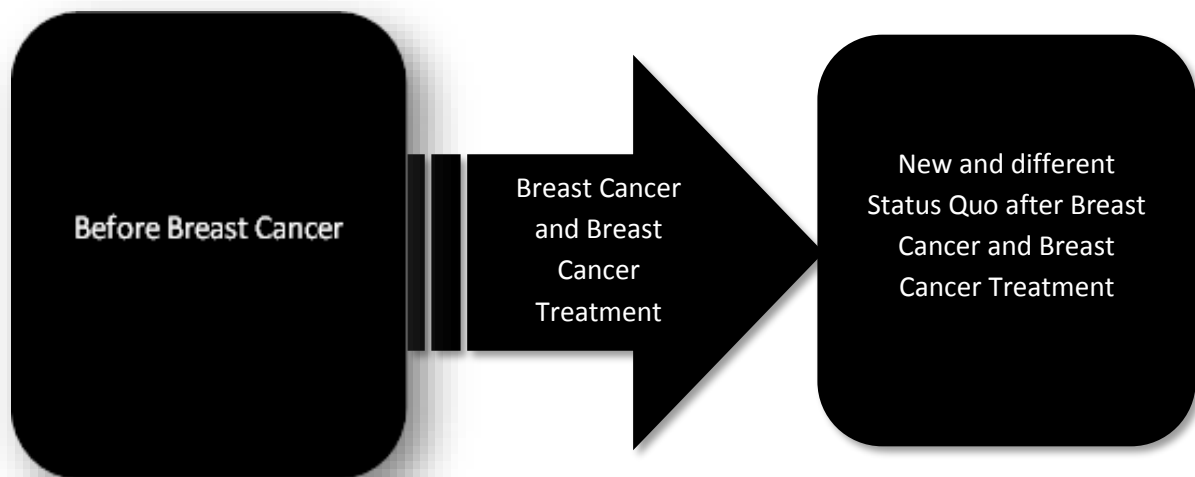
*Patient II* struggled to make peace with, and accept her constant anxiety for her scheduled breast surgery. I explained to her that she could accept the fact that anxiety will be part of her anticipation for the surgery and that she could adapt to it by making peace with the reality that fear and anxiety in a situation like hers, is normal and inevitable. It was discussed with her that different treatment processes generate different fears and expectations as well as emotional and physical outcomes, and that every time she starts a new treatment modality, there would be new fears and emotions and losses (Spiegel, 1995). I emphasised that she should also allow herself at the end of a treatment stage (e.g. when she was finished with chemotherapy) to celebrate it and end it off on a 'good note' and to allow herself some rest before the next treatment starts (e.g. the surgery). It makes it easier to 'compartmentalize' her treatments and properly end it of when finished and to either 'celebrate' the end or to 'tick it of' as finished. By doing so it will feel like something with a beginning and an end (Dockery, 2014; Pratt, 2015). Another aim was to talk about making peace with the realism that she could not, while undergoing active cancer treatment, do certain things the way she was used to (e.g. her house chores). She could make practical changes and amendments, and still function on an acceptable level. She still had eight radiotherapy sessions left, and it was explained to her that at the end of her treatment, there would be a transition time to shift again from being an active cancer patient for nearly a year, to a 'normal' person again (Dolbeault et al., 2009; Henselmans et al., 2010; Stanton et al., 2005). It would take some time for her to get used to the idea that although she was finished with the treatment, there were still lingering side-effects, such as tiredness, short-term memory loss, mood changes and some biological dysfunctions that would be a constant reminder of her cancer (Brem & Kumar, 2011; Fallowfield & Jenkins, 2015). It was discussed that she could not go through all these losses and changes and challenges and yet be the same as before the cancer. Even as a couple, they would function on a different level (Baider et al., 2000; Surbone et al., 2000). In answer to this, she said:

*“...I can feel that there are areas in my personality that has changed, for instance, I am more relaxed about my emotions, especially negative emotions and can now share it. ...I also allow myself more things in life without feeling unnecessary guilty. ...and I don't think so rigidly about things anymore.”*

This fits in with Carver (2005) who said that a longer term aim would be to empower the breast cancer patient with general life skills and mechanisms beyond their current spell with cancer.

*Patient III:* I explained to her that part of the reality of breast cancer is that after the cancer treatment she would experience some short-term and permanent changes. She can learn to accept the chronicity of her illness through acknowledging her negative and 'scary' emotions and not be afraid of negative feelings and that the new challenges must be 'tackled' as they come. I explained to her that she might feel anxious and scared every time that she have to see her oncologist for a follow-up session, but that, that 'type' of anxiousness is normal and she must allow herself to feel that but can then also use her coping-skills to deal with the anxiety. It was also emphasised that she must look after her depression (which was diagnosed and explained during the previous session) and if the symptoms did not get better she should make an appointment with her oncology team and discuss it with them, confirming again that depression and anxiety are treatable conditions and not abnormal in her situation (Mello et al., 2013).

To summarise adaptation, I used a diagram to demonstrate that because of all the losses and changes that breast cancer patients go through during treatment, they can never be the same as before the cancer, or look at themselves and the world the same way as before.



**Figure 7.2: Diagram to illustrate the “journey” from breast cancer to the “new” status quo after the treatment.**

#### **Theme 14: Cognitive and behavioural techniques (CBT):**

The therapeutic process based on the cognitive theory, consists of helping the breast cancer patient to become aware of her automatic flow of thoughts when distressed and to identify and modify these dysfunctional thoughts (Beck et al., 1979; Chand & Grossberg, 2013; Cook et al., 2015; Hofmann & Smits, 2008). Behavioural techniques are used to bring about functional changes in behaviour, regulate emotions and help the cognitive restructuring process (Cook et al., 2015).

An element that a therapist must take into consideration when doing cognitive therapy with a cancer patient is the importance of individual differences. People view the world differently and they differ in their emotional and behavioural responses to hardship. A person’s experience, perceptions and impact of having an illness might influence the interpretation and reaction to the illness (Carver, 2005; Hulbert-Williams et al., 2011). During the diagnosis and active treatment phase when patients are dealing with the immediate acute impact of the diagnosis, treatment decisions and side-effects, CBT is more problem-focused and psycho-educational. For example, it then concentrates on active coping responses such as re-creation of new goals to survive this active phase of breast cancer where in the re-entry phase, the focus might be more on cognitive reconstruction of irrational thoughts, coping strategies, acceptance and adaptation to the new status

quo and learning to live with the chronicity of cancer (Anderson, 1992; Low et al., 2008; Mullan, 1985).

*Patient II* experienced acute negative thoughts and worries during the chemotherapy due to unpleasant and unexpected side-effects. The therapist explained to her that these negative thoughts and worries should be seen as 'normal' and realistic in this abnormal and stressful situation and that she can learn to acknowledge and allow these negative thoughts, speak about it and put in to the perspective of her illness and treatment (Cook & Salmon, 2014). Although she had to allow herself to acknowledge negative thoughts, she should be careful not to invest energy in it and keep it active, but rather focus on making new thoughts which will make her feel better and more in control over her thoughts and feelings (Hofmann et al., 2010; Manne et al., 2009). It was explained how to cognitively manage her thoughts and emotions by taking control over it through allowing herself to go through the negative emotions, sharing it and asking herself what can she change regarding her circumstances and what must she accept and adapt to. She could also learn to distinguish between realistic negative thoughts (e.g. she is scared of the cancer treatment and its unfamiliarity) and irrational thoughts (e.g. her constant thoughts that she must prove herself to her husband and family and that she still has to do everything around the house in spite of the cancer). She could learn to identify her most basic dysfunctional beliefs about herself (e.g. "I must prove myself to my husband and children" and "I am only useful if I do all the housework myself") and replace it with realistic and true thoughts "I do not have to proof myself after thirty years to my husband and children" and "we all have a good and solid relationship, they accept me for who I am, even now with the cancer." (Beck & Greenberg, 1984; Beck, Liese & Najavits, 2005). The patient understood that there is a difference between irrational thoughts, which is not true and is modifiable and negative and anxious thoughts that has to do with her cancer and uncertain future that is 'normal' in the situation and can be acknowledge and accepted (Beck et al., 1984; Cook & Salmon, 2014).

We concentrated on behavioural changes in terms of her fatigue and day to day behaviour and on using different behaviour to divert her focus away from her negative and anxious thoughts. Behavioural techniques are used to bring about



functional changes in behaviour, regulate emotions and help the cognitive restructuring process (Cook et al., 2015). She could learn that, to stay in the present moment with behaviour and thoughts, she could lessen worry and rumination of negative and disruptive thoughts, allowing for more adaptive responses to what was happening in the moment (Luoma & Villatte, 2012). By focusing on the present rather than constantly worrying about the future, she could deal more effectively with her stressors, such as the side-effects of her chemo, which could lead to her feeling anxious and depressed (Hofmann et al., 2003; Kabat-Zinn, 2003). In therapy it is important to teach a patient to respond thoughtfully (consciously) rather than automatically (unconsciously) to stressful situations and negative emotions.

*Patient III*, who had longstanding issues with her husband concerning their relationship in general and his lack of support during her illness (which was contributing to her feelings of depression), was inclined to concentrate a lot on how he was in the past and his negative and unsupportive behaviour. It was explained to her that by working through her disappointment in her husband's lack of support and 'watching' her thoughts and trying to focus away from it, she could change how she felt and reacted towards him now (Beck et al., 1979; Chand & Grossberg, 2013; Cook et al., 2015). It was explained to her that she could not change what had happened in the past between them, but could consciously concentrate to change her behaviour and expectations towards him then. Instead of dwelling on negative thoughts about her marriage, she could try to focus away from that and replace it with more positive and constructive thoughts and behaviour. She could also try to involve him more in her treatment process, instead of just expecting of him to know what to do and to talk to him about what she needed of him. Her feedback was that he was helping her more in and around the house and took her for long drives "to forget about her illness" and so she could rather concentrate on his supportive behaviour and helpfulness instead of only concentrating on the things that he did not do or did not do right.

She was extremely stressed and anxious before her surgery, and she was preoccupied in the sessions with that and also at home where she was constantly anxious about the surgery. The importance of breathing- and relaxation exercises

were emphasised again to relax her body, but also to serve as a distraction away from the anxiety (Golden-Kreutz et al., 2005; Hulbert-Williams et al., 2011; Mulan, 1985). She could for instance ask her husband to go for a walk or do an activity to divert her mind from the extreme stressful thoughts. Focusing on activities that require concentration and physical activity are valued to take the mind of threatening emotions and anxious thoughts and that by spending time with others was also helpful. This was not only as emotional support but also as distraction through positive activities (Logan et al. 2006, Lauver et al. 2007, Giske & Artinian 2008). It was explained to her that she could allow herself to feel anxious and scared because of the upcoming surgery for it is not irrational or abnormal and not to ignore the negative thoughts or to feel guilty about it but rather accept it and then to move on to 'new' thoughts that she could create to feel better and more in control (Cook & Salmon, 2014; Hofmann et al., 2010). Harris (2009) and Luoma & Villatte (2012) support this by saying that a patient must allow negative thoughts to come and go, rather than holding onto them. Because the patient was inclined to feel overwhelmed in stressful and negative situations she could become quite passive (in terms of behaviour and thoughts). She understood the value and benefit of taking action when in a situation that affected her in a negative way.

An important goal that was of much value for both *Patient II and III* was to learn to adopt goals that were related to their newly changed life context (the acute and busy treatment phase). This was in response to the demands posed to their health condition (Carver, 2005). It was explained to them that in the beginning, after the breast cancer diagnosis and during the active treatment, they might struggle with basic day to day achieving of their goals because of acute side-effects like nausea, pain and fatigue. The lack of achieving their goals (e.g. to go to work every day, or to run the household as before and to maintain certain tasks) could make them feel incompetent and useless, therefore it is important to engage in new, more suitable goals. An example that suited them both was, in terms of their alopecia, to find out where they can buy a wig and headbands and to start wearing them and experimenting with it, or how to survive a chemo session, what to take with them to make the time shorter, or whom to take with them, or how to work around their fatigue. The patients also learnt that together with these new and changed goals, they would experience new and challenging emotions that needed

to be talked about, dealt with and put in proper perspective of the cancer. It was important for the therapist to encourage and facilitate re-engagement in new goals in order to help reinstate a sense of purpose (Brennan, 2001; Carver, 2005; Thompson et al., 2013). By explaining the reason(s) why “normal” day to day goals were hard to reach (in terms of specific side-effects and symptoms) already made the patient feel more competent and useful. The patient also needed to understand that if a goal was hard or impossible to achieve, it had to be replaced by a new or altered goal that could be achieved. Often after finishing with cancer treatment, some previous goals could again be implemented and achieved, but that there were also some goals that would have to be changed in the long run because of permanent changes due to the cancer and cancer treatment. This supports the general conception that the new life circumstances imposed by a cancer diagnosis and its treatment can threaten the pursuit and attainment of an individual’s personal goals (Carver, 2005; Stefanic et al., 2013; Thompson et al., 2013; Wrosch et al., 2003).

*Patient 1* reported back that she had experienced a lot of negative, destructive and fearful thoughts regarding her cancer when she was busy with chemotherapy saying:

*“...The thoughts seemed to just mill around in my head all the time.”*

She said when she felt anxious or had anxious thoughts it helped her to get up and walk around or to find an activity to distract herself from her negative and stressful thoughts. We talked about the negative and anxious thoughts during her active cancer treatment, especially the chemotherapy. I reinforced the fact that conscious diverting and focusing away from anxious thoughts could enable her to gain objectivity (detachment) towards negative and fearful thoughts and make her feel more in control of her emotions and behaviour (Beck, 1970; Cook & Salmon, 2014; Giske & Artinian 2008; Jacobsen & Jim, 2008; Lauver et al. 2007, Logan et al., 2006, Vahdaninia et al., 2010). It was explained to her that instead of changing negative thoughts she could learn to accept that it is normal in emotional situations like her breast cancer and she could rather focus on how she relate to the thoughts. Thoughts were not to be taken literally as statements of truth or fact, but rather simply represented verbal activity (Cook & Salmon, 2014; Hinton & Gaynor,

2010). Therefore, instead of changing the negative thoughts she could rather focus on creating new thoughts which made her feel more in control over her thoughts and feelings (Hofman et al., 2010). I explained that if she thought constantly about her negative feelings and problems and losses, she could begin to over-identify with her thoughts and intensify it in such a way that it could become the truth and also very powerful (Luoma & Villatte, 2012). It could then contribute to her depression and anxiety (Morris & Shakespeare-Finch, 2011; Osborn et al., 2006). On the practical side it is better to identify and acknowledge negative and destructive thoughts instead of becoming caught up in the thoughts, allowing it to come and go rather than holding onto them (Luoma & Villatte, 2012).

Because of the patient's high level of anxiety, I have also explained the benefits of muscle relaxation and deep breathing exercises, explaining that deep breathing is not only a biological method to reduce anxiousness, but a way to focus away from stressful thoughts and concentrating on something else. It is concluded that progressive muscle relaxation and diaphragmatic breathing together with cognitive behavioural and mindfulness stress reduction are all effective treatment methods for reducing stress and anxiety that accompanies daily life and chronic illness (Berger et al., 2015; Jerath et al., 2006; Liza, 2011; Norton et al., 2014). The relaxation- and breathing exercises made a lot of sense to the patient and she fully understood how these skills could help her with her anxiety.

*Patient IV* – because this patient had a problem with her weight and its continuous contribution to her feelings of depression, it was an aim in therapy to talk about changing her behaviour to start getting active again which could result in losing some weight. It was explained to her that personal goals (such as losing weight and to start exercising) would provide her with a purpose, structure, direction, rewards and meaning and that the successful and continued pursuit of these goals could be a key source for her psychological well-being (Brandtstädter & Rothermund, 2002; Stefanic et al., 2013; Wrosch et al., 2003). We have identified short term goals and proposed ways to meet it, e.g. to start walking short distances which would both restore some of her energy and she could start losing weight. She could make an appointment with a dietician and start with a healthy eating program. According to Dimeo and colleagues (2008) there are increasing

scientific proof that exercise can markedly reduce cancer-related fatigue and can avert the patient's appearance. It was also established that she could participate in hobbies and activities where she could be creative and live herself out instead of thinking (ruminating) about how "bad and passive and different" she felt. It was emphasised that it is always better to start with 'baby steps' so that the new behaviour can be sustainable. We worked on the principle that behavioural techniques could be used to bring about functional changes in behaviour, regulate emotions and help the cognitive restructuring process (Cook et al., 2015). I explained that she could learn to accept that negative thoughts and fears regarding the future and her cancer and the continuous follow-up appointments with the oncologist were realistic and even 'normal' in her situation and that it was impossible not to have negative or unhappy thoughts (Cook & Salmon, 2014). She could learn to become consciously aware of her present thoughts without being judgemental in her awareness, e.g. not to feel angry or guilty about certain thoughts, but rather accept it and change her attitude towards it and allow herself more flexible and adaptive responses to her present challenges (Brem & Kumar, 2011; Driessen et al., 2010).

*Patient V* asked to specifically learn new skills to handle stressful thoughts and situations better for she experienced a lot of worries about everything and she knew that too much stress was not good for her cancer. I explained to her that there are different mechanisms of handling stress in terms of her thoughts, which is called the cognitive process and her behaviour (the things she does), which include conscious relaxation exercises and deep breathing. Because the patient had gained weight during her cancer treatment, we made it a therapeutic aim to talk about getting active and losing weight and she had already cleared it with her oncologist that she could start exercising again. We talked about short term goals regarding her weight and fitness that was realistic and achievable and that would fit her current health status and which would give a purpose and direction in her life (Brandtstädter & Rothermund, 2002; Stefanic et al., 2013; Wrosch et al., 2003). She said that before the cancer she was fit and that she was looking forward to participate in formal exercises again.

Another therapeutic aim was to take control of her thought process by starting to identify her negative and irrational thoughts and to accept the fact that negative and anxious thoughts are normal in the aftermath of breast cancer and instead of fighting against it, to rather accept it without being judgemental for thinking it (Cook & Salmon, 2014; Luoma & Villatte, 2012). Instead of trying to change her negative thoughts the whole time, she could acknowledge it and then focus on new thoughts or behaviour that are more constructive and positive and could make her feel more in control over her thoughts and feelings (Hofmann, et al., 2010). We talked about the importance of focusing on the here and now, to think what was happening around her then, what she was experiencing then and what she could do then to feel better, for example: if she had distressing thoughts, she could phone a friend and talk to her, make a cup of tea, do something in or around the house, go for a walk or engage her husband and child in activities to take her mind off the anxious thoughts (Beck, 1970; Cook & Salmon, 2014; Lauver et al. 2007; Logan et al., 2006; Luoma & Villatte, 2010). The therapist described that if she thought perseverated about her negative feelings and problems it will further contribute to her feelings of depression and anxiety, but by distancing herself from these thoughts she could distinguish between thoughts and reality, e.g. that by thinking something does not mean that it is true and that thoughts are just thoughts and not necessarily a reality (Morris & Shakespeare- Finch, 2011; Nolen-Hoeksema et al., 2008; Osborn et al., 2006). The point to make for the patient is that thoughts are only as powerful as you allow them to become and that by over-identifying with your thoughts and intensifying them in your mind it can become the truth (Luoma & Villatte, 2012). The patient said:

*“I feel excited about the new skills, it makes sense to me and I cannot wait to start doing it.”*

#### **7.4.1.4 SEX THERAPY**

Breast cancer patients and their partners can benefit from brief sex therapy with techniques including cognitive and behavioural coping skills, psycho-education regarding self-esteem, loss of desire, fatigue and menopause and sexual communication between partners (Derogatis & Kourlesis, 1981; Fobair & Spiegel, 2009; Hughes, 2008; Hummel et al., 2015; Masters & Johnson, 1970; Park et al.,

2009; Schover, 1991). These elements all form part of this study's intervention plan during the psycho-therapeutic sessions. An important aim of sex therapy, when working with breast cancer patients, is to remove the barriers in sexual health communication between the oncology team and the patient and to initiate conversations about sexual functioning (Derogatis & Kourlesis, 1981; Park et al., 2009). Sex therapy further aim to teach cancer patients to acknowledge their sexual changes and challenges and to develop new skills to enhance their sex lives and intimate relationship during and after breast cancer (Jun et al., 2011).

**Theme 15: Talking about sex: Why cancer patients don't talk to their oncologists about their sexual issues and where they can talk about it:**

I have found during the psycho-therapeutic sessions with the patients in this study that they all had, including patient II, who has experienced very little sexual changes and difficulties during her cancer treatment, a need to speak to somebody about the changes and challenges of their sexuality and sex lives. They have made it clear that they've felt relieved and exited to have expressed their sexual concerns with a professional person in a safe and trusted environment (Eker & Acikgoz, 2011) and they have expressed their eagerness to learn more about their sexuality regarding their cancer. There is sufficient evidence in the literature that, although breast cancer patients and their partners need information about their sexuality during and after cancer treatment with a health professional, such information delivery is often inadequate or completely absent (Fallowfield & Jenkins, 1999; Flynn et al., 2012; Gilbert et al., 2014; Hautamäki-Lamminen, Lipiäinen, Beaver, Lehto & KellokumpuLehtinen, 2013; Hordern & Currow, 2003). I have found that regardless of the ages of the patients in this study, they all had an interest in their sexual functioning and in addressing their sexual issues or concerns (Hautamäki-Lamminen, Lipiäinen, Beaver, Lehto, & KellokumpuLehtinen, 2013; Hill et al., 2010; Lindau et al., 2007).

*Patient II* had, during our first consultation, started to talk about her sex life spontaneously, explaining that they still had a "normal" sex life which she found quite reassuring, saying that:

*“...Although I am very tired at times, our intimate relationship is as good as ever. ...we still have normal sexual activities.”*

I have supported this through explaining to her that sexual activity cannot be harmful during cancer treatment and can continue throughout the treatment and can in actual fact be an integral part of her recovery process, giving her a feeling of “normality” (Fobair & Spiegel, 2009; Hill et al., 2010; Schover et al., 1984; Taylor et al., 2011). When asked, she said that nobody in her oncology team had spoken to her about biological changes such as menopause or sexual changes due to the treatment and that the topic of sex had never come up. We talked about possible sexual changes later during or after the treatment. The patient said that if that is the case, she would like to have more information about the subject. Hill and colleagues (2010) have recommended that women who are treated for breast cancer, regardless of their marital status, age, cancer type or stage, should be informed by their physician of the sexual impact of their cancer and their cancer treatment.

*Patient III* experienced sexual difficulties before the cancer diagnosis and treatment and asked if it would be possible for me to see her husband and talk to him about their sex life, saying:

*“...I would like to improve it, I haven’t enjoyed sex for a while and maybe we can then feel closer to each other.”*

It is reported in the literature that cancer patients often find it important for their partners to be included in discussions about their sexuality with the health care professionals and for the professionals to make provision for it during the therapeutic process, or to encourage the cancer patient to involve her partner in the therapeutic process (Flynn et al., 2011; Gilbert et al., 2014). I have encouraged her to talk about their sexual difficulties before the cancer diagnosis and now, valuing the fact that by giving her a chance to talk about her sexual hardship can be therapeutic in itself (Derzko et al. 2007; Nusbaum et al., 2003). I have asked her how she felt talking about sex and she said:

*“...I have never before spoken to anybody else about it, not even my husband ...it makes me feel so relieved to talk about sex and excited to change our sex life.”*



Both *patients II and III* seemed relaxed and relieved to talk about their sex lives in therapy and without much prompting they have shared details about their sexuality and sexual activities, both relevant to the cancer treatment and otherwise. I have used the benefits of early conversations with the patients regarding their sex lives to get them comfortable and give them the opportunity and confidence to discuss any questions regarding their sexual functioning and illness and to realise through that, that it is acceptable to talk about sex and sexuality. Derogatis and Kourlesis (1981) felt that many sexual problems can be solved by just the opportunity to discuss it in a safe and professional environment without in-depth sex therapy. The patients regarded the conversations about their sex lives very therapeutic and very positive. Neither of them had even once spoken to their oncologists or any member of their oncology team about sex or their sexual functioning for there was never a “platform” for conversations regarding that and they didn’t know, before it was explained to them in psychotherapy, that there could be effects on their sex lives. Both reported speaking about sex as very liberating. Flynn and colleagues (2012) felt that clinicians may need to take on greater responsibility for informing patients about all potential side effects of treatments, including sexual side-effects whether or not patients raise specific questions regarding it. Park and colleagues (2009) reported that all patients, regardless of their age, marital status or stage of cancer, should be asked about their sexual issues throughout the whole trajectory of their illness in order to provide practical information so that the patients can understand their situation and help them to come to terms with their feelings about their sexuality and cancer.

*Patient I* said, when asked about her sexuality and sexual functioning:

*“We did have sex during the time of my treatment, although less. ...to me everything was about survival and while sex was not my priority then, we still had a good sex life and it did me good when it happened.”*

But as the treatment went on, she experienced some sexual problems and when asked, she said she never felt that she could have had a conversation about her sex life with her oncologist,

*“We didn’t have that type of relationship or open communication. Sex was never a subject of discussion...nobody has spoken openly to me about my sexuality or sexual functioning ...I had to struggle through that on my own, not having the confidence to ask about it.”*

We talked about the fact that sexual issues are not always integrated into routine cancer care as yet and that it could cause feelings of neglect from the oncology team for not raising the subject of sexuality or providing adequate information regarding it. This is very prominently underlined in literature by recent authors (Flynn et al., 2012; Gilbert et al., 2014; Krouwel et al., 2015; Reece et al., 2010; Sporn et al., 2015). I have explained to her that other breast cancer patients in her position experience more or less the same sexual uncertainties and functioning as she does and that experiencing difficulties in her sexual functioning is normal, but treatable (Derogatis & Kourlesis, 1981; Stead et al., 2003). By giving her the opportunity and safe environment to speak about her sexual functioning and concerns and through normalizing her fears and issues, she felt much more liberated about this “forbidden” subject, saying:

*“...I understand my sexuality and sexual functioning much better and feel more in control in this area of my life.”*

*Patient IV* appeared comfortable speaking about how she felt about her sexuality and sexual activities regarding the cancer and her worries. She asked during the third therapeutic session, during a conversation regarding sex, if she could bring her partner with her the next time to discuss with him their lack of proper sexual activities due to her cancer treatment and other issues that they have. This was acknowledged and arranged for the next therapeutic session. Cancer patients often need to include their partners in their therapeutic process (Flynn et al., 2012; Gilbert et al., 2014; Hordern & Currow, 2003; Hordern & Street, 2007). When asked how she feels about talking to the therapist about her sexual functioning she said:

*“Being able to talk to you about sex and putting it in the framework of my depression and cancer, I understood my lack of sexual functioning better now without feeling so guilty and ‘abnormal’ about myself anymore.”*

She said, when asked, that she and her oncologist, in spite of a good relationship, never discussed her sexual functioning.

*Patient V* who presented with severe marital problems asked during the second therapeutic session if she could bring her husband to a session because she felt that he did not understand the influence that the cancer had on her and their relationship, especially their sexual relationship. She said that they had a good sex life before the cancer without any problems and that even during the course of the cancer treatment their sexual functioning was active and good. I positively reinforced their sexual activities during the treatment, explaining that she can look at it as a good and positive part of her recovery process and that by keeping up an active sex life can play an important role in their sexual functioning as a couple (Hill et al., 2010; Taylor et al., 2011). When asked about their problems, she said:

*“Our sexual problems only started after the hormonal treatment. ...I then realised that I didn’t get enough information regarding my sexual functioning, especially menopause, or what to expect of my body and sexual functioning.”*

She understood that information regarding sexual issues are often not integrated into routine cancer care which can cause the patient to feel uninformed and unsure about sexual changes and who to talk to (Hordern & Currow, 2003; Hummel et al., 2015; Park et al., 2009). We discussed the importance of talking about her sexual issues and the therapeutic opportunity to learn new skills to improve their sexual problems and it was emphasized that the sexual difficulties and uncertainties that she was experiencing, was normal in her situation.

- **Sex therapy: psycho-education**

Psycho-education, which is the combination of education and information with elements of psychological therapy, was found to significantly improve sexual knowledge and understanding in the cancer framework (Brotto et al., 2008). During the sex therapy interventions of this study I have predominantly made use of psycho-education as a technique believing that breast cancer patients often only need education and basic practical information about their sexual situation to help them understand their cancer related sexual functioning and to assist them with their sexual expectations in the future (Derogatis & Kourlesis, 1981; Park et

al., 2009; Taylor et al., 2011). I have worked from the believe that this (sexual) information should be repeated several times during the psychotherapeutic process to make sure that the patient stays in contact with her sexual functioning throughout the course of her cancer journey and feel comfortable talking about it (Schover et al., 1984).

**Theme 16: Explaining the most important and relevant sexual matters to the patients:**

- **Menopause and loss of libido:**

Menopause and premature menopause was a prominent and well-discussed occurrence in this study especially concerning the three patients already finished with their treatment. The reason for this long-term side-effect can be due to the use of Tamoxifen and AIs which are hormonal treatments and are used for up to five or more years after active treatment. The implications of this long term treatment can cause the rehabilitation process of the breast cancer patients to include living and managing the side effects of on-going treatments and must be clearly explained to the breast cancer patient (Brem & Kumar, 2011; Ewertz & Jensen, 2011; Kuo et al., 2008; Siegel et al., 2012). Apart from menopause, chemotherapy and hormonal treatment can also cause low androgen levels, which can be linked to lower sexual desire and can consequently result in less sexual activity (Fobair & Spiegel, 2009; Meier, 2010).

*Patients II and III* who were in the middle of their acute treatment side-effects, did not yet experience any treatment related sexual side-effects.

*Patient II* who was still pre-menopausal said that she experienced no symptoms of menopause yet or any changes regarding her sexuality:

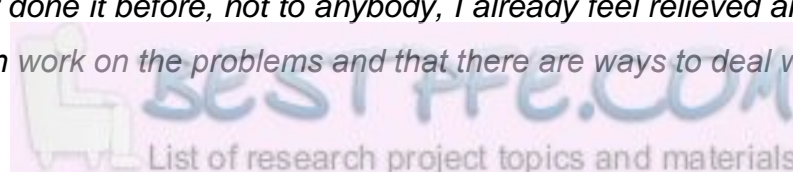
*“...up till now nobody has spoken or mentioned anything about menopause or possible menopausal symptoms.”*

The absence of communication and information can leave people with cancer feeling unprepared for the sexual side effects of cancer and treatments (Stead et

al., 2003). I explained to her that menopause could be a side-effect of chemotherapy, which is then called a chemically induced menopause and can happen rather quickly. The symptoms of chemo-related menopause and 'normal' age-relevant menopause are the same and include: stopping of menstruation, hot flushes, heart palpitations, an inability to concentrate, short term memory loss, possible weight gain, mood swings, a decrease in sexual desire and vaginal dryness (Dean, 2008). It was explained to her that vaginal dryness can cause pain and discomfort during intercourse and it is important to use (when in that situation) enough lubrication, which can be bought over the counter in a pharmacy (Derzko & Elliot, 2007). By knowing the symptoms of menopause she could at least be prepared for it when it happened.

*Patient III* was the only patient that had already been menopausal for a couple of years. She was comfortable and familiar with the symptoms. She was a good example of a cancer patient that firstly focused on her treatment and was in complete survival mode and was not sexually active during this time, not just due to her severe side-effects of the cancer treatment, but also because her sexuality and sexual activities was already compromised because of marital and health problems. This was confirmed by authors such as Katz (2005) and Taylor and colleagues (2011) stating that immediately after a cancer diagnosis, anxiety and worry for survival is so immense and issues of mortality all consuming, that sex is not necessarily an immediate priority. It was also her experience that their sexual problems laid with her husband's chronic illness and accompanied erectile dysfunction, but has declared herself (more than once) ready and open to participate in any form of sex therapy or conversations when her cancer treatment was over and her husband's sexual dysfunction was sorted out. She was also willing to assist her husband in sorting out his sexual problems and would go to whatever lengths it would take from her to help him in order for them to have a healthy sex life. When asked about how she felt talking to me about her sex life, she said:

*"...I have never done it before, not to anybody, I already feel relieved and I realise now that we can work on the problems and that there are ways to deal with it."*



*Patient I, IV and V* who were all three pre-menopausal before their breast cancer diagnosis and younger than the two state patients, experienced many more challenges and uncertainties regarding their abrupt menopausal symptoms and lack of libido. I noticed that all three of them, who was treated by different oncology teams, had experienced the same lack of information and knowledge regarding menopause and relevant sexual functioning regardless of the fact that all three of them were in longstanding permanent relationships or marriages. It is clear in the literature and was explained as such to the patients that with the absence of communication and information regarding menopause and relevant symptoms and side-effects, they and their partners could feel “abnormal” and unprepared for the sexual side-effects of the cancer treatments (Deeks et al., 2011; Gilbert et al., 2014; Stead et al., 2003; Vogel et al. 2009).

*Patient I* said, when asked about sexual problems, that because of her treatment, she was on Tamoxifen for the next five years, (she had already been on it for more than a year and a half), she has a complete lack of oestrogen:

*“...it happened rather suddenly. I was completely surprised and overwhelmed by the unexpected sexual changes during and after my treatment...I was not prepared for the suddenness of the menopause. ...even the way my body reacted sexually has changed.”*

This patient explained that menopause was only mentioned briefly by the oncologist as a side-effect of the chemotherapy and Tamoxifen,

*“...but It was never discussed at length or what I could expect of my body and emotions, or what I could do to adapt to the situation...I have a lot of questions about my menopause and lack of libido, but did not find answers up till now.”* She also said:

*“...the one thing that me and my husband don't understand is my complete lack of libido or any form of sexual contact or conversations because before the cancer we had a good and satisfactory sex life.”*

Because of her lack of knowledge I have explained that the abruptness of the onset of her premature menopause and the severe symptoms which she was not prepared for, were all due to the lack of oestrogen because of the cancer treatment. By talking about menopause and its symptoms and learning new skills to manage it, she could still have a fulfilled and quality sex life. She also understood that a 'chemical induced' menopause had an immediate effect on the body and mind, and what she was experiencing was normal for her situation. We also discussed the chronicity of these changes and that accepting and making peace with her permanent menopausal status and complete lack of oestrogen were imperative and a prerequisite for adapting to this new status quo. The 'practicalities' of sexual functioning in menopause was further explained, for example, the lack of vaginal lubrication and accompanying pain and discomfort with intercourse, the using of vaginal moisturizers and lubrication to counteract this and to learn new practical skills, such as maintaining longer foreplay to be biologically ready for intercourse and to reach an orgasm. It was further explained that sex had a lot to do with a mind-set and because of the lack of oestrogen and androgen there is an accompanying lack of desire or libido or natural drive to have sex and that having sex becomes more a process of thought than biology. It was explained that in the framework of this, it was important for her (and her husband) to understand that the lack of her sex drive was a biologically driven component and had nothing to do with their feelings or attraction for each other or that there was something wrong with their relationship. This was also described in literature by Brem and Kumar (2011) and Kuo and colleagues (2008).

*Patient IV* said that both she and her partner suffered from a low libido, both due to biological reasons and that it worried her,

*"...but I didn't realise that my treatment has also contributed to a further collapse in my libido."*

I explained to her that the lack of her natural sex drive was more biologically inclined due to her cancer and depression and the treatments for these conditions and had nothing to do with how she felt about her partner (American Cancer Society, 2010; Mimoun, 2011; Strasser et al., 2006). It was also explained to her

that a lowered spontaneous sex drive is not abnormal in her menopausal situation (Derzko et al., 2007). We discussed the biological implications of her current menopausal state (she has stopped menstruating after the first chemo infusion), in terms of mood swings and emotional reactions, hot flushes, insomnia and irritability which could worsen her symptoms of depression even further. She needed to be aware of this as not to stress because of her 'double' depressive symptoms, but understand it in the light of her menopause. The literature described the relation between menopause and oestrogen decline and depression (Brem & Kumar, 2011; Fann et al., 2008; Navari et al., 2008). Because of her history with depression and her chronic use of anti-depressants, it could also influence her libido and sexual activities, for most anti-depressants are prone to decrease the biological drive even further. She was on Wellbutrin which increased sexual arousal and orgasm intensity and overall sexual satisfaction (Faller et al., 2011; Fobair & Spiegel, 2009; Krychman & Katz, 2012). It was also explained that menopause can have a huge impact on a woman's sexuality because of changes in her body including vaginal dryness and loss of vaginal tissue elasticity, which can affect her sexual interest and sexual functioning (Dean, 2008; Hughes, 2008). These physical changes could inspire her and her partner to adopt new sexual behaviour, for instance, to make more effort with foreplay, taking more time to stimulate each other, knowing that it might take longer to get ready for sexual activity and pleasure. The using of lubrication was also discussed as a tool to make sexual intercourse easier and less uncomfortable and painful and she was encouraged to acquaint herself with the different lubrications (Derzko et al., 2007; Krychman & Katz, 2012; Reece et al., 2010). The patient admitted that she was not familiar with cancer treatment induced menopause and was not ready for the changes in her body and already compromised sexual functioning. She felt relieved that she at least understood why she felt and reacted different sexually than before the cancer. This is again evidence that when a breast cancer patient has not sufficient information and knowledge regarding the effects of cancer treatment on their bodies, they feel unprepared for the sexual side-effects and may feel disappointed with their health professionals for their lack of information and support (Deeks et al., 2011; Gilbert et al., 2014; Stead et al., 2003; Vogel, et al., 2009).



*Patient V* who is the youngest of the five patients was affected the worst by her premature menopause and has asked the most questions. She also presented with marital problems which developed during her breast cancer treatment due to various cancer side-effects, including that of sexual- and body changes. Although her oncologist had explained to her that she would go into menopause because of the medication, she felt that she needed more information regarding her hormone medication and time to talk about it, saying:

*“...I understand that this will also affect my sex life and I must drink it for five years ...I want to know how menopause works and what it will do to my body since it is something unfamiliar to me.”*

Young women who are diagnosed with breast cancer often suffer sexual side-effects and challenges during the most sexually active years of their lives. I explained that early menopause could be a shocking and overwhelming experience for a young woman like herself (Brem & Kumar, 2011; Deeks et al., 2011; Ewertz & Jensen, 2011). I described premature menopause to the patient as something that happens very abruptly comparing with natural age-appropriate menopause where the body and mind has time to adapt to the changes because they happen over a period of time. I further explained that premature menopause is an occurrence outside the normal life course which can have a significant impact on the physical and emotional well-being of a person. Menopausal symptoms, especially vaginal dryness, can be a physiological disappointment for woman over 50 years of age and even more so for younger women and must be explained very clearly with practical skills to counteract it for the young woman to still have a good and fulfilled sex life (Deeks et al., 2011; Fobair, & Spiegel, 2009). I have worked here on the principle of Derzko and colleagues (2007) that giving and explaining the more practical elements of sexual functioning regarding menopause will be beneficial for cancer patients, providing them with active and constructive skills to deal with lifelong symptoms and sexual changes. Because this patient said that she was completely unfamiliar with menopause, I explained all the menopausal symptoms and the impact on her body and her sexuality. This included: hot flushes, night sweats, sleep problems (insomnia), possible weight gain and slowed metabolism, possible thinning hair and dry skin. Menopause

could also influence her mood causing mood swings, irritability and even depression and a decreased libido, explaining it as a lessened sex drive. There can also be a risk of losing bone density, causing early osteoporosis (American Cancer Society, 2014; Brem & Kumar, 2011; Ewertz & Jensen, 2011). The use of lubrications was explained in detail, acknowledging the fact that younger women who are in a new and unexpected menopausal status have most probably never had to use lubrications before and do not necessarily have the confidence to talk it through with their oncology team (Derzko et al., 2007; Hughes, 2008). The therapist explained that together with managing the biological symptoms of premature menopause, accepting something unnatural as this occurrence lies in the conscious mind and is a psychological process. It is about making a decision to make peace with it and accept it through working through her emotions and being open to learn new behaviour to adapt successfully to an 'older' body with a 'young' mind (and husband). It was emphasised that despite the fact that there is a lot of negative side-effects to the hormone treatment, it has the benefit of reducing her risk of the cancer coming back.

It was explained to her that a decreased libido goes together with menopause and meant that she would not always, in a biological way, feel in the mood for sex the way she had before the cancer. Together with the lessening of oestrogen, there is also a lessening of androgen, which is the hormone that "orchestrates" the biological drive to want sex (Brem & Kumar, 2011; Kuo et al., 2008). To overcome this biological lack of a sex drive, she could consciously think and 'talk' herself into sex and mentally prepare herself. She could still enjoy the act even if she was not automatically aroused from the beginning. Communication about the lack of a libido or a lower than usual libido is important so that her husband could understand that her lower libido was a biological side-effect of her cancer treatment and had nothing to do with him or her feelings towards him and that they could work around that instead of getting stuck with it.

I have explained to patients I, IV and V that, because of their loss of libido and lack of a biological sexual urge, they could also use other motivations for engaging in sexual activities, such as to generate emotional closeness to their partner or

reassurance of a loving and intimate relationship and partner satisfaction, which all can contribute to her own quality of life (Derzko et al., 2007).

- **Breast cancer treatment vs. self-esteem and body image**

Breast cancer patients undergoing cancer treatment are exposed to changes in their physical appearance such as the loss or disfigurement of one or both breasts, scars from surgery and skin changes related to radiotherapy, lymphedema, alopecia and weight increase (Dean, 2008; Falk et al, 2010; Krychman & Katz, 2012; Kuo et al., 2008; Reece et al., 2010; Sbitti et al., 2011). These changes are all related closely to physical appearance and body image and it is important for the therapist working with this patient population, to address these issues during psychotherapy.

*Patients II and III* spoke little about their body-image concerning their active breast cancer treatment and the influence on their sexual functioning despite the fact that both of them suffered from alopecia. Most of our sessions were consumed by their active emotions and grievances and practicalities regarding their cancer treatment.

It was established through studies that patients who feel better about their bodies, as in the case of Patient II, because of the support and positive feedback from their husbands, have stronger believes in their own ability to reach out to others for support, maintain a more positive attitude towards the cancer and remain active, self-efficient and independent, which was especially noticeable during the sessions with this patient (Anagnostopoulos and Myrghianni, 2009; Baxter et al., 2006; Sheppard & Ely, 2008; Wilmoth, 2001).

*Patient III:* experienced initial doubt regarding her looks when her hair fell out after the first chemo infusion, especially because she felt her husband didn't support her enough or made her feel better about it, saying:

*"I feel self-conscious and don't feel like going out in public."*

We have talked about practical interventions, such as wearing head bands or her wig, but because of her emotional status due to her active cancer treatment, she

did not experience changes to her body-image at this stage, or relate it to their sexual problems.

The apparent lack of serious cancer related body image problems from the two patients still busy with their treatment supported literature which indicates that sexual problems worsen beyond the first year after diagnosis and treatment, causing abnormal sexual and body image patterns to develop with time (Dean, 2008; Katz, 2005; Rosenberg et al., 2012). It also supports conclusions that there is a significant correlation between body image and age, especially for young premenopausal women as is the case with the next three patients, who have been noted to have reported a more prominent loss of femininity, infertility and various sexual problems related to early induced menopause (Dalton et al., 2009; Jun et al., 2011; Nozawa et al., 2013; Rosenberg et al., 2012; Wong-Kim et al., 2005).

*Patient 1* said that her total hair loss together with the changed shape of her breast after the surgery affected her self-image seriously;

*“...the cortisone that I used has caused insomnia and swelling, I didn’t look the way I did before the cancer. ...the form of my body and weight has changed drastically ...I even thought back then that my children were ashamed of me looking ill and swollen and with no hair, but realised later that it was my own projection and insecurities about my illness and how I looked at myself.”*

She said that even then after all that time her self-image was still compromised and that she could make a connection between how she looked and felt physically and how her body reacted sexually. She felt her changed appearance and accompanied sexual functioning was just another thing to worry about together with all the other worries regarding the cancer and depression and anxiety. The aim of the therapeutic intervention here was to explain the changes in her body due to the cancer treatment and the impact it had on her self-esteem and self-confidence. I aimed to have taught her self-compassion, which is the ability to accept her the way she is now and show self-directed kindness in this “abnormal” and stressful situation. It was explained to her that she could develop a more positive body image perception of herself through acceptance of her physical

changes and losses and develop a new 'after-cancer' self-esteem in a very conscious and practical way. By doing this, it could help her to feel self-worthier and more sexually acceptable for her husband (Anagnostopoulos & Myrghianni, 2009; Przewdziecki et al., 2012; Wilmoth, 2001). She said that although she had a breast reconstruction operation, her breasts did not look the same and the scarring reminded her on a daily basis of her cancer and impacted her self-confidence. Although reconstructive surgery can alleviate the impact on the sexual body image to some degree (Markopoulos et al., 2009), this patient felt that in spite of her reconstructive surgery, she was still self-conscious about her breasts and changes in her body-shape which was affecting her sexuality. I attempted to teach her to be non-judgemental toward her own body and to accept her physical 'imperfections' and limitations in order for her to improve her sexual body image. Because this patient experienced her changed body so prominently and negatively, it was discussed that, in a very practical matter, she could for instance change the way she dresses to suit her body shape and weight gain and learn to at least like her 'new' body more. These principles were supported in literature through authors such as Przewdziecki and colleagues (2012) and Wilmoth (2001).

*Patient IV* had gained a lot of weight due to the cancer treatment and had consequently suffered from a very negative body image and negative feelings about her appearance. She said during the first session (without prompting) that she wished to talk about her weight and self-image and self-confidence somewhere during the therapeutic sessions. Here the aim of psycho-therapy was to help her develop a more positive body image through kindly accept herself and showing self-directed empathy while in a difficult situation (Anagnostopoulos & Myrghianni, 2009; Przewdziecki, Sherman, Baillie, Taylor, Foley, & Stalgis-Bilinski, 2013; Przewdziecki & Sherman 2016; Raes, 2011). Through mindfulness she could learn to accept her present appearance rather than focus on achievement of ideals or perfection and to concentrate on neutral observation or reality instead of body avoidance or harsh self-judgement (Alberts et al. 2012). It was also discussed that she could engage in a plan of action to lose weight e.g. to start with a proper diet plan together with a dietician and to implement an exercise plan. The therapist explained to her the benefits of losing weight in terms of her self-esteem and sexual self-esteem, but to be realistic about her goals and to take small steps

at a time. Apart from her weight problem, the patient also had a problem with her breast, saying:

*“...where I had the lumpectomy the breast is now different from the other one and it makes me feel self-conscious. ...and that even with clothes on, it looks different...I really feel very self-conscious.”*

She said the whole change of her body was also contributing, not just to her body image and sexuality, but also to her feelings of depression. I asked about breast reconstruction and she said that although she had never in the past thought about it, she was now seriously considering it. She also said that it would be much later in the future. It was explained that apart from making peace with her ‘different’ breast and changed body she could also, through practical behaviour, e.g. changing her clothes to hide her breast deformity and emphasizing other body parts she felt more comfortable with. She could wear something like a camisole to bed to ‘hide’ the scar when participating in sexual activities to make her feel less conscious of her scar and to help her focus away from her body and to enjoy sex more. These therapeutic principles were supported by authors like Dimeo and co-workers, (2001), Hassan and Amin (2011), Przezdziecki and co-workers, (2012) and Przezdziecki and Sherman, (2016). The patient said that her dissatisfaction with herself has also seeped through to her general functioning and social interaction;

*“...it has influenced my whole job performance, I feel that I don’t perform in my job as I used to...”*

Where it was explained that she should concentrate to be consciously aware of irrational thoughts regarding her self-image, for example “I am not good at my job anymore” or “I can’t remember as well as before the cancer” with more rational and ‘true’ thoughts such as “the cancer did not change my intellect or ability to do my job” or “the cancer did not take away my qualifications” or “even if I struggle with my short term memory, there are ways to help me with that.” She could also through self-compassion apply greater cognitive flexibility to change her irrational thoughts regarding her self-image as well as by focussing on things and activities

that would make her feel better e.g. taking up hobbies again instead of just thinking about how bad and passive and different she was (Martin et al., 2011; Przewdziecki, 2013).

*Patient V.* Various authors have written about the hardship of infertility after breast cancer treatment in young patients (Corney & Swinglehurst, 2014; Deeks et al., 2011; Gabriel & Domchek, 2010). However, this patient who had a hysterectomy at the age of 34 years, said her family and husband were more concerned about the fact that she could not have another child than she was:

*“I am satisfied with only one child, but my husband did not necessarily share my vision. ...I realised that I am the mother of my child and must make a decision regarding to see him grow up or have another child and see neither of them growing up. ...It was more a question of survival than having another child.”*

In terms of her body-image she said because they were still young and sexually very active;

*“...I was scared that my husband would be repulsed by my body and I immediately decided that I will have reconstruction surgery as soon as it was possible. ...my husband will not see me without breasts”*

She said she felt good about her reconstructive procedure and that it contributed positively towards her self-image, but the fact that she had gained weight during her cancer treatment as well as her persistent tiredness which made her feel “unsexy” and “older” than her actual years, had affected her body-image negatively. Literature agrees with this, saying that breast reconstruction following total mastectomy has benefits in terms of body image to some degree (Albornoz et al., 2013; Emilee et al., 2010; Fallbjörk et al., 2010). She wanted to talk about her weight and her body-image, saying that being unfit and weighing more than before the breast cancer, was a negative experience for her, influencing her sexual body image. Later in the therapeutic process when she was exercising again she said it made her feel more social and “in” with the “normal” crowd;

*“...I really feel normal again; being able to do normal things every day ...but know there’s a long road ahead to get used to my ‘new’ body.”*

We talked about developing a more positive and realistic body image perception and to make an effort to accept herself through a softer approach and a non-judgemental attitude towards herself. We also talked about going to the gym and exercising again as it could be very beneficial not just for her body weight, but also for her fatigue, improving of her memory functioning and an overall feeling of general well-being (Anagnostopoulos & Myrghianni, 2009; Dimeo et al., 2001; Hassan & Amin, 2011; Przewdziecki et al., 2012). I emphasised the practical elements such as the way she dresses, especially with lymphedema and the weight that she had gained and to go (for instance) regularly if possible for body and facial massages to “spoil” her body and keep it in good order and by doing that to concentrate on the rest of her body that was not affected by the cancer. It was also explained to her that negative and deconstructive thoughts about self-image can be identified by herself and consciously be changed to positive and friendlier thoughts (Przewdziecki et al., 2012, 2013; Przewdziecki & Sherman, 2016).

I have found that all three patients who were already in remission had severe and continuous problems with their body image and sexuality right from the start. This escalated throughout their treatment and after the treatment. If they could have participated in sex therapy from an early start as indicated in literature, they could continue to have, to some degree, felt sexually attractive and functional and would have been able to sustain and conserve better courage and self-esteem throughout this process (Fobair, & Spiegel, 2009; Jun et al. 2011; Schover et al., 1984). This again emphasises the importance of early referral to a psychologist by the oncologist (Park et al., 2006; Surbone et al., 2013).

- **Behavioural changes and cognitive restructuring of inflexible thoughts**

Because of the nature of the breast cancer patient’s most prominent sexual dysfunctions (arousal- and orgasm problems due to menopause, intimate issues



and physical- and body-image changes) the therapist has, through years of experience, learned to rely on a more behavioural contribution to intervene with this already emotionally traumatized population. Sensate focusing, as a behavioural technique, focusses on teaching new skills to a patient who suffers from any form of sexual or intimate difficulties, and its basic principles are often used when conducting sex therapy. One of the advantages of sensate exercises is that it can be implemented in stages so that small changes in behaviour like holding hands can precede larger changes in behaviour such as trying new and different sexual activities, which will be beneficial in the long run for the “new identity” of the breast cancer survivor (Reece et al., 2010; Weiners & Avery-Clark, 2014). Behavioural- and sensate focusing goes very well together with the flexibility model which is a cognitive and behavioural approach to changing perceptions and thoughts regarding sexual functioning when confronting with acute or chronic sexual changes or dysfunction (Barsky et al., 2006, 2010).

In contrast with the three patients (I, IV and V) that was in remission and had experienced and presented with outspoken sexual issues, Patients II and III did not merit specific behavioural or cognitive interventions concerning their sexual functioning.

I have rather focused on providing them with relevant information regarding their current sex lives in the framework of their acute cancer treatment and aimed to include them in open discussions about their sexuality to make them comfortable and used to talking about their sexual functioning. This eased possible anxiety around post-cancer sexual changes, minimize the negative impact on their intimate relationship and to motivate them to discuss their sexuality with their partner (Rasmusson & Thome, 2008; Perz, Ussher, & Gilbert 2014; Vogel et al., 2009).

During her cancer treatment *Patient I* experienced the inability and a lack of confidence to speak to her husband about the absence of her sexual interest and bodily and sexual changes due to her cancer treatment. What had made the problem worse was that they had no prior sexual problems before the cancer and that she did not have the proper knowledge as to what was happening to her in terms of her sexual functioning. This lack of communication has led to a total

abstinence of their “normal” sexual interactions during her treatment also resulting in a decrease in their intimacy. I explained to her that it was not abnormal for a person in a sexual crisis to stay away from sexuality, feeling scared that any form of touching might lead to sex or ‘misleading’ the partner that they can have sex when they are not in the biological or even psychological position to do so. The therapeutic aim here was to talk about going back to basic sexual behaviour, e.g. touching and caressing each other without actual penetration and learning to look at yourself from a new angle, accommodating your body changes due to the cancer treatment. I have learnt from experience working with breast cancer patients, that they often find it difficult to start with the sexual act, when it is biologically possible to have sex again, after a period of sexual abstinence. Therefore it is less threatening for them to “go back to the basics” first to regain some of the trust and comfort with each other’s bodies. I have explained the “practicalities” of sexual functioning within the framework of menopause as the patient’s biggest challenge, for example, the use of lubrication, prolonging the foreplay stage and implementing new strategies, e.g. massaging, different positions and techniques to reach an orgasm. This was also a good time to invest in a new book or books to gain more knowledge about different and new sexual skills that was applicable in her situation. I have explained the importance of sharing the information with her partner. Talking about sex with your partner, together with touching and caressing first before sexual intercourse, is also a safe way to start implementing your sexual functioning again. I used the principles of sensate touching. I did not use the whole sensate exercise program due to time constraints on the study. Patients often only need to understand their unique situation and basic information of what to do to get back on track. The most important aim here was for the patient to become more comfortable with her own changed body again. She had to connect with her husband on an intimate level again through talking to him about her emotions and sexual issues. She had to discuss her uncertainties and explain to him what she felt sexually and talk to him about her sexual desires (Masters & Johnson, 1970; Weinera & Avery-Clark, 2014). At the end of the session it was decided to involve her husband the next time for a couple’s session and the patient revealed that this session in particular meant a lot to her, saying:

*“...I really understood my own body better now as well as the permanent impact from the breast cancer on my sexuality ...because of the new skills and knowledge I feel more relaxed about sex and intimacy and instead of it just being another loss and stressor in this ‘jungle’ of effects and side-effects of the breast cancer, I found it is something that can be treated and resolved.”*

Although there were lengthy therapeutic discussions about her self-esteem and body image, as well as about her chemotherapy related menopause, the sex therapy with *Patient IV* was only done with her partner in a couple’s session. This will be discussed under the heading ‘Couples’.

When *Patient V*, started with the therapeutic process she just had a hysterectomy two weeks earlier and couldn’t engage in sex for six weeks. According to her, her husband found this quite challenging. We then discussed the importance of intimacy and the therapist explained that when the sexual act was not possible (as with her situation then) it was important to still stay involved with cuddling, kissing, spending time together, caring and talking. When the time was right for sex again, it would be much easier to resume one’s sexual activities when there was some form of sexual intimacy as opposed to when there was just a complete absence of bodily contact or any form of intimacy. Intimacy could help to maintain a form of normality in the face of cancer, reassuring the patient that there is still a life away from cancer and healthy activities to participate in. Because of all the changes that she is going through in her body and mind, she could see this as a learning curve to experience with new sexual techniques to help her with her lack of libido and difficulty to reach an orgasm e.g. by using liberal quantities of lubrication, invest in longer foreplay and try new sexual styles and positions that will work in their unique situation. This is when the six weeks of sexual abstinence due to the hysterectomy was over. This was also a good time to talk to her husband about what she was experiencing sexually and to include him was the most important part of this new sexual journey. This fits in with literature which underlines teaching and encouraging communication between partners about their sexual experiences, sexual desires and boundaries (Masters & Johnson, 1970; Weinera & Avery-Clark, 2014).

- **COUPLES AND SEX THERAPY**

Although the focus of this research study was primarily on the breast cancer patient and her own needs and experiences during individual sessions, the therapist has tried to see the patient's partner at least once in a therapeutic session. The aim with a couple's session was of getting information from the partner regarding his experience of his partner's cancer, but also to educate both partners about the diagnosis and treatments side-effects. It was also to promote their mutual coping and support processes and include treatment modalities that make use of specific sex therapy methods that address open sexual communication skills and sexual and body image concerns (Hummel et al, 2015; Mann & Badr, 2008; Nicolas, 2013).

### **Theme 17: Couples Intervention when Treating Breast Cancer Patients:**

As a therapist working with breast cancer patients, it is important to understand that regardless of the cancer- and cancer treatment stage of your patient, the cancer self creates unique challenges for the marital relationship. Successful adjustment will be influenced by how well the couple integrates the cancer into their lives and relationship, even more than the circumstances of the cancer self (Manne & Badr, 2008). Within this framework I have noticed that each partner had a different perception and interpretation of the meaning and influence of the breast cancer on their lives with completely different expectations of their partners and their support. As a couple, they also had a different pace with their own adaptation and acceptance of the cancer experience.

*Patient II* who had a very well adapted marriage for 39 years has reported, from our first psycho-therapeutic session, the good and appreciated support from her husband. She has also made her own conclusion regarding her better emotional and sexual adaptation during her cancer treatment, saying that it was because of his "soft approach" and effective support both sexually and emotionally. Because of this on-going support the whole time that she received the treatment and during our therapeutic process, she has never requested or mentioned that she would like to involve her husband in our therapy sessions. She did report that after each of our sessions she told him what we had discussed and that he was always interested in our discussions.

*Patient III* on the other hand, has asked from the very first session whether it would be possible for the therapist to see her husband:

*“...to explain to him what I am going through with my cancer and what I feel ...He doesn't understand my emotions and fears.”*

She has also asked whether I would please speak to him about their sex life, for she would like to improve it.

I saw this patient's husband after the fifth individual therapeutic session on his own although the session was booked for both of them. There was a change in her chemo time and the chemo sister came to fetch her in our scheduled time. The session was then held with the husband alone, which had turned out to be a good session, with good feedback from the patient after the session. The most important and positive information from the husband was that he was looking forward to this session to understand his wife better, saying:

*“...I know I am far more practical than my wife and do not always understand her emotional reactions and what to do about it.”*

Without asking any questions he explained that they had already made some practical adjustments along the way and that he was helping with the housework and cooking more than previously. He said that he realised that the breast cancer diagnosis was very traumatic for his wife, especially her hair falling out and the absence of her daughter and that they were both worried about their financial situation. I explained to him the side-effects of the chemotherapy (e.g. the tiredness and chemo-fog) and her emotional reactions and fears regarding her cancer and future and emphasised the chronicity of the cancer and effects in terms of their marriage and sexual functioning. I told him that his wife had confided in me about their sex life (or the lack thereof) and asked to talk to him regarding that. It was explained to him that despite his chronic illness and accompanying sexual problems they could still have a healthy sex life, but they will have to make an effort to talk to each other about their needs and expectations, taking into consideration her cancer and making plans together on how to improve their sexual and intimate functioning. They could consider reading books about sex or try out new ways of engaging in sexual activities without intercourse. I suggested

that he should make an appointment with an urologist to sort out his (chronic) sexual problems and because this was out of the range of the psychologist, the patient had to be referred to a medical specialist (Derzko et al., 2007).

I have encouraged him to communicate more freely and openly with his wife about his and her emotions, reminding him that different people have different emotional needs and that he needed to ask her what she saw as support and what her expectations of him were. It was explained to him that a marital relationship is a source that a person can “draw on” in a crisis situation (Manne et al., 2008), and when there are negative feelings and resentment towards a partner, as was the case with his wife, feeling he is not properly supporting her the way he should it will negatively influence her treatment outcome and future adaptation. Her uncertainty and anxiety regarding the scheduled breast operation was also explained in terms of the normal reaction of anxiety in this type of situation and that there are ways to manage it, e.g. to relax through deep breathing, to engage in “outside” activities like walking or driving around together and for her to plan and prepare his meals for when she is in hospital, making her feel more in control. His support during this time before the surgery would help her to cope emotionally and prepare herself for the operation and I explained to him that feeling close to and being cared for by a partner can make this whole cancer experience more bearable (Nicolas, 2013).

One of the aims of the session was to initiate conversation with the patient’s partner about their sexual functioning and for him to feel comfortable discussing their sexual matters. Another goal was giving education and basic information about their current situation and to look at alternatives to manage and adapt to the situation (Derogatis & Kourlesis, 1981; Park et al., 2009; Zhou et al., 2015).

At the end of the session he said:

*“I never thought that I would talk about sex to a ‘stranger’ and yet it I feel so relieved that we have spoken about it ...it was bothering me for such a long time.”*

He also said that he was willing to attend to his sexual problems and make an effort to better their sex life, also saying:

*“...I feel that I know more how to help and understand my wife...”*

*Patient 1* - There was a scheduled session booked for the couple with the aim of sex therapy. Information from the husband verifying what his wife had experienced concerning the lack of proper information from the oncology team about her sexual changes before, during or after the cancer treatment. He confirmed that it had put unnecessary pressure on them as a couple, not knowing what to expect and what was normal and what was not. They also didn't know what timeframe to put on their sexual changes and whether it would change back to how it was before or if it was a permanent situation. This lack of communication was confirmed in studies showing many participants reporting that they were not properly prepared for sexual changes or equipped to cope with it, leading the couple to feel negative and unprepared for the unexpected, often long-term sexual side-effects of cancer (Flynn et al., 2012; Gilbert et al., 2014; Hill et al., 2010).

The couple stated that they did not talk about the patient's lack of sexual interest and sexual functioning during the active treatment or survivorship phase. Neither did they discuss changes in her body, admitting that it was easier to talk 'through' a professional person regarding their uncertainties and questions. It was noticed with this couple that their impaired communication about their sexual problems and changes caused them psychological distress and influenced their marital satisfaction in a negative way (Hordern & Currow, 2003; Milbury & Badr, 2013; Murray, 2010).

We agreed that the aim of the session would mainly be to explain specific side-effects of cancer such as menopause and to improve their sexual and intimate communication. During the course of the session the couple started to speak freely and comfortably about their emotions and thoughts about sex and sexuality throughout the whole cancer excursion. Both were frustrated and uninformed regarding the patient's complete lack of libido due to her menopause, and could not understand their lack of sexual activities. Before the cancer they had a good and satisfactory sex life and they haven't expected this. It was explained to them that this is not an abnormal occurrence because cancer is such a traumatic disease which affects all forms of functioning, sex life included, and that

oncologists do not always discuss sexual matters or prepare the patient for sexual side-effects.

Chemo related premature menopause was explained in terms of the biological side-effects and immediate effect on the body and especially the impact on the libido, which is a very big loss in their relationship, leaving the husband relieved that her absence of a libido had nothing to do with him or her feelings about him. It was a “mere” side-effect of the chemotherapy. As a couple they were encouraged to explore the changes and losses in their sexuality and intimacy due to the cancer and communicate it with each other and share their feelings regarding it.

The husband said that he now understood the chronicity of his wife’s cancer and that they both have to work hard to create a new and exciting status quo that will work for both of them. I also mentioned to the husband that he had to acknowledge his own losses regarding their changed and challenged sexual functioning as well as that of his wife’s. By understanding their “new” sexuality, they could use it to grow individually and as a couple. I have experienced both the patient and her husband to have exceptionally good insight in this therapeutic session and they both expressed their enthusiasm to start implementing the new skills.

*Patient IV* - This patient requested that her partner had to participate in one session so that he could understand what she was going through in terms of her emotions and especially her depression. She also wanted him to understand how the cancer treatment had affected her self-esteem and sexuality. She wanted to hear from her partner himself how he felt about their sexual relationship. During the couple’s session the partner explained that the emotional side of the cancer was the worst for him, seeing her suffer like that and:

*“...not always knowing what to do or how to help her...it was hard for me to see her enduring so much turmoil.”*

Because the patient was so depressed, the therapist had given her time to talk about how she felt and then explained to her partner the relationship between depression and cancer treatment, especially chemotherapy which could cause a chemical depression (Brem & Kumar, 2011; Fann et al., 2008; Navari et al., 2008).



It was also explained that with her history of depression she was more prone to develop depression after the cancer treatment, but that there were interventions to relieve the symptoms of depression such as medication which they both were familiar with and therapeutic techniques. I also suggested possible alternatives such as admittance in a clinic for mood disorders. We discussed the temporary changes after her breast cancer treatment such as her tiredness and short term memory incapacitation, as well as some of the permanent changes, especially body image, which the patient had a big problem with. It was explained to them that they should allow themselves to go through an emotional process to make peace with and accept their losses and changes due to the breast cancer and share their feelings with each other. Communication is a practical way to start, e.g. exchanging needs and expectations, instead of expecting your partner “to know” what you are feeling or what you need. It is important to talk about emotions and not to feel that you have to be strong all the time. Showing emotions is not a sign of weakness, but a commitment to understand and support each other.

Both partners were comfortable to speak about their sexuality and they both agreed that their sex life was not as good as it could be due to their low libidos. In both cases it was because of biological reasons. They never felt threatened by it because their intimate relationship and functioning was good and well established, yet the patient felt they could improve their sexual functioning. Her unexpected menopause and relevant symptoms were explained in terms of the psychological implications like mood swings and biological implications like the lack of vaginal lubrication, with emphasis on the influence it had on her already low libido. It was important for the patient and the partner to know that the patient’s low libido had nothing to do with their relationship or how she felt about her partner, but everything to do with the breast cancer and treatment and also in her case, the depression and anti-depressant (Dean, 2008; Deeks et al., 2011; Rivas-Vazquez et al., 2000). It was explained that because of the biological nature of premature menopause, it would require changes in their sexual behaviour, e.g. to employ different behavioural techniques such as extended foreplay and the use of generous vaginal lubrication. I experienced this couple more open-minded when it came to sexual activities and they had no problems with more flexible thoughts and actions concerning their sex life. I could therefore use some principles of

Hughes (2008) suggesting more liberal alternatives to help the patient with her low libido and lack of sexual functioning, for instance, experiencing with new alternatives such as watching erotic movies together or the use of a vibrator for extra stimulation. It was important for both of them to understand that it might take longer now and more effort for the patient to get physically ready for intercourse. They were also encouraged to work around the patient's severe tiredness by setting up a time table for their sexual activities during the time of the day (or night) when the patient felt less stressed and tired and to make an effort to participate in sexual activities again to keep their relationship on a healthy level. It was explained that to develop a new and more active sexual life will take time and effort and creativity and the more they talked about their sexual thoughts and needs and "plans" to improve their sex life, the more "normal" and part of their lives it will become. The patient talked again about her negative body-image, especially the scar and weight gain, and although her partner had assured her that it made no difference in his feelings about her, I explained that to "side-step" the problem, she could wear something like a camisole to bed to "hide" the scar and to take the focus away from her scar. They both agreed to commit themselves to working towards a better functioning and to use creativity and effort to improve their sex life.

*Patient V* asked from the first session if her husband could come to hear from a professional person what she went through with her cancer and was still going through. She was very disappointed when he didn't want to come to a session in the beginning, but she had convinced him and he did participate later in a therapeutic session. He accompanied her during the fourth therapeutic session and made it very clear that he was only there because his wife had asked him to come, he had no questions (when asked) and said that he would listen to what will be said in therapy. The patient then requested that I should explain to him what were discussed during the previous sessions regarding the changes in her body especially due to the menopause and what they could expect in terms of her sexually in the future. I started with the menopausal symptoms, because it was so unexpected and had such a devastating impact on their sex life. I explained the biological side-effects, namely hot flushes (which she experienced a lot), problems with her sleep pattern, weight gain and a possible slower metabolism and a

decrease in her natural sex drive as well as a lack of vaginal lubrication. I explained to him that his wife was in full menopause, because of the cancer treatment and that her body would sexually react in a different way and that the menopausal symptoms were permanent which would mean permanent changes from both of them. I also explained the subsequent sexual side-effects of the hormone medication that she would be using for the next five years. She would need his support and understanding to make peace and accept her body and still be a good sex partner to him. Menopause did not mean that they would not have a good and regular sex life, but there would be differences and changes and by accepting that they will be able to develop new skills for a new sexual status quo. One of the changes due to menopause is the use of vaginal lubrication and moisturising during sexual activities because her body won't produce natural lubrication anymore and that they can also consider different techniques or "aids" such as dilators and vibrators or erotic reading or movies to enhance their sex life again. This was based on the principles of giving basic information about the couples sexual situation and challenges and to provide them with new alternatives (Derogatis & Kourlesis, 1981; Hughes, 2008). They were encouraged to make a conscious effort to explore the changes in their sexuality and intimacy and communicate their desires and needs to each other (Fobair & Spiegel, 2009; Hordern & Currow, 2003; Hughes et al., 2011).

I explained to them that by talking to each other about how they felt or what they experienced they could develop an emotional closeness which can enhance their overall relationship and which they can "draw" from when they are in a crisis (Hill et al., 2010; Manne and Badr; 2008; Mann et al., 2014). They both understood that neither of them could be the same (sexually or emotionally) as before the cancer, and that only through an emotional process of grieving, accepting and making peace with the breast cancer, will they be able to "create" a new way of living and growing as a couple. It was important for them to look at themselves as a team working together towards an end goal and not just an individual on an individual journey. The patient explained to her husband that she was scared that he might reject her sexually and that she sometimes felt self-conscious about all her physical changes and that she needed to hear from him that he still wanted her

the way she was. His reply was that he was still very attracted to her sexually. He said:

*“...I only understand now the adjustments that we have to make ...I never thought about any of it in this light...”*

He also said:

*“I will make an effort to accommodate the changes and I understand your emotional reactions better.”*

The patient said that by hearing him say this already made her feel more accepted by him. They were reminded that breast cancer is a chronic condition that will “ask” for life-long adaptations through learning and implementing new skills, that it will take time and remains a team effort.

#### **7.4.1.5 END OF THERAPY: THE FINAL VOICES**

This is an overall feedback given from the five breast cancer patients about their therapeutic experiences. Most of the feedback was acquired during our last sessions through specifically asking about their experiences during the sessions. They were invited to give their opinions and to make comments regarding these experiences. I also acknowledged other feedback that was given spontaneously by the patients after some of their other sessions. The feedback was divided in general feedback and sexual feedback.

#### **The feedback of Patients II and III:**

*Patient II:*

- General Feedback:

She commented during the third session that she felt more in control of her emotions and life, saying:

*“...the mere fact that we speak every three weeks gives me the courage to carry on, knowing that I can vent my feelings to somebody that understands the process of chemotherapy and somebody that is outside of my family ...speaking about the*

*cancer treatment and getting information about it, makes it less unfamiliar and scary and worrying.”*

During our last session, she said that by the time that she had to go for her second surgery (the radical mastectomy), she understood what “normal anticipation” anxiety meant and could then handle the anxiety about the surgery and the time away from her family more comfortably when in hospital. She said:

*“I went back in my head to all the stress handling skills that you have taught me, especially the time management and how to control my thoughts through focusing away from my stress and to talk about my emotions.”*

She said that those skills helped her a great deal through her ordeal with the surgery and long wait for the radiation therapy. She said that the two months while she had to wait for the results of the surgery was also very tense for her, but she could put her fears in the framework that it is “normal” to be scared when waiting for medical results. She said because of the therapy:

*“...I now talk very easily about my cancer experience and emotions to others... and it is not just helping me to cope but I also help other people now with their emotional hardship ...I have a completely different outlook on life after the cancer and I feel that I can make a difference in other people’s lives.”*

The feedback from this patient regarding the therapeutic sessions and her healing process was:

*“...because of our sessions I could understand step by step what was happening to me and could prepare myself for every phase during the treatment process...I cannot even imagine how different it would have been if it was not for the sessions because I was so “clueless” about everything ...most of the things that we had discussed during the sessions and the skills that I have learned, were not previously part of my frame of mind or practical world.”*

She said that to her, one of the most important parts of the therapy was the “practical” advice that she got, for example the time management skills and “the resting” during the times that she was so tired without feeling guilty. She said

knowing that if she didn't understand something she could ask me the next time and it made her feel more relaxed. She mentioned that something she found very positive about therapy was that she could talk about anything without feeling guilty or ashamed and that by talking to a therapist, she did not have to "burden" her family with certain things, saying:

*"...I have also learned to listen to my own body and talk to other people around me about how I feel and also allow myself more things in life without feeling unnecessary guilt and that I don't think as rigidly as before."* She ended this off by saying:

*"I am extremely thankful for the privilege to have been accepted for this study and being part of a process that might help other breast cancer patients ...I don't think that I would have known to go and see somebody like a psychologist..."*

- **Relationship and Sexual Feedback:**

She said because we talked about their sexual activity right through the therapeutic process from the beginning of the sessions,

*"...it made the changes in my body more 'natural' and less scary for me and my husband."*

She said she appreciated the fact that I have made the intimate and sexual side part of the therapy,

*"I don't think that I would ever have just talked about that to anybody, knowing now how the treatment can affect my sexuality, I can prepare myself for the changes to come..."*

*Patient III:*

- **General Feedback:**

At the end of the first session the patient had already said that she was glad that she could talk about her feelings regarding her cancer and other personal issues and after the third session she said:

*“...If you haven’t offered your services in the beginning of the treatment, I don’t think I would have ever spoken about my problems to anyone...every time that I have spoken to you, I felt relieved, especially when I realised that we can work on the problems and that there are ways to deal with it.”* She also said:

*“...for me, the cancer treatment is more ‘complete’ with our sessions because no matter what comes up, even at home, I can come and discuss it with you.”*

Her feedback after the session before the surgery was that she felt better for just talking about her anxiety and that she would do the practical things that was discussed during the session like preparing her husband’s food before her surgery and to do something to focus away from her anxiety. She understood the anxiety and did not have to “fight” it but could let it go and concentrate on the surgery and on getting well. She said that she learned that depression is not something to feel ashamed of and she was looking forward to start with her anti-depressant to feel better, saying:

*“...through learning to focus on the ‘now’ and to accept and control my negative thoughts and focus on more positive thoughts, I feel that my emotions are more manageable and bearable ...through talking to you I have learned to understand my stress better and that there are always alternatives to handle a stressful situation ...I feel better and lighter when I speak about my feelings.”*

She also said that for the first time she had identified friends and family with whom she could talk to and share her emotions without feeling guilty.

About the sessions she said:

*“...I have never before seen a psychologist and did not even know what they were doing ...I feel so blessed to have been able to see you and understand the cancer better and my husband and daughter.”*

- **Relationship and Sexual Feedback:**

*“...for the first time, me and my husband is in a much better relationship with each other, we speak more about our emotions and what we feel ...one of the positive things that had come from my cancer is a better relationship between me and my husband ...we have started talking about sex and have decided that after the cancer treatment is over, he will go to a urologist...”*

She felt that the psychotherapeutic session with her husband had made a big impression on him, saying:

*“...he is making an effort to understand me and the cancer and he supported me much better than in the beginning ...there is a big change in our relationship, even our communication about our sex life has improved drastically.”*

She said that the mere fact that they were talking about their sexual relationship, made it a much more approachable topic between the two of them:

*“...I feel that at last we are going to do something about our sex life and I am looking forward to it. “*

*Patient I:*

- **General Feedback:**

She said at the end of the session:

*“...just talking to somebody with knowledge about the psychological side of breast cancer already makes me feel better and more 'normal' ...I am looking forward to have therapeutic sessions with you regarding my issues around the cancer and my functioning now.”*

It was two years after her last treatment and she said:

*“I feel that my rhythm is more or less back to where it was before the cancer ...being back at work and being able to participate in all my 'normal' daily activities makes me feel more like myself again.”*

She said that the psychotherapeutic sessions helped her understand that she will be confronted with the aftermath of cancer for the rest of her life, but that she has



learned to accept this through conscious efforts to grieve her losses and new coping skills for a new but 'unwanted' chronic situation. She said:

*"It was important for me to work through my trauma step by step by talking about it and working through all the emotions before making peace with it and accepting it."*

She also stated that by receiving relevant information and knowledge regarding the effects of cancer and the treatment, especially on her emotions and sexual functioning, was one of the things that she valued most during the therapeutic process, saying:

*"...there has opened a lot of doors for me in terms of understanding what I am experiencing and why ...I have learned to look at my life goals from different angles and had to redefine and adjust some of it, especially in terms of my work."*

In summarising, she described the therapeutic process, saying:

*"It was a lifeline to grab onto when I was drowning in a sea of emotions, which dragged me back to the surface again! ...By understanding the reality of what the cancer was doing to me and to be able to put my own feelings and experiences in context was what brought me back to the 'surface'."*

- **Relationship and Sexual feedback:**

She said that both she and her husband have benefited from the session regarding their sexual functioning,

*"...we were both clueless as to what was happening to us sexually ...understanding the biological and psychological side-effects of early menopause on my sexuality and especially my lack of libido, has clarified a lot of my behaviour for me and my husband ...We now look at our sexuality through the framework of the cancer instead of taking it personally and it makes sense to develop a new outlook on not only sex, but also intimacy..."*

Patient IV:

Because the patient's depression made out such a large part of her functioning, that the most of her feedback revolved around her depression and then about the cancer.

- **General Feedback:**

The patient replied, when asked about for feedback, that:

*"...talking to you from the first session did me very good ...every time that we speak about my depression and the fact that I can do something about it, made me feel stronger and less 'abnormal' ...knowing and understanding the influence of depression on my life and relationship also made me feel more positive about myself."*

The patient said about the therapeutic process:

*"...It was helping me so much with myself and I feel much more 'clever' now in how to understand and handle myself in terms of my depression, especially after the cancer."*

To this patient, knowledge had played a big part in her therapeutic process, she felt that if she knew and understood things, whether it was the depression or the cancer treatment, she could cope better and be more comfortable with it. She said:

*"...I understand now that some of my symptoms like the tiredness and lack of energy and drive and even lower sex drive can be both part of my depression and side-effects of the chemotherapy, and it makes me feel less of a victim of myself and circumstances."*

She also requested further sessions with me, saying that she felt that it would help her to talk about her emotions from time to time with somebody outside her relationship and friends and that it would benefit the recovery of her depression and the reinforcement of her new skills.

- **Relationship and Sexual Feedback:**

This patient said that she understood that different things were influencing her sexuality and sexual activities, such as her depression, the cancer treatment and her low and “affected” self- and body-image. She said after the session with her partner that they started to improve their intimacy even more,

*“We have started to participate in activities with much more touching and sexual closeness without being necessary sexually active ...I am feeling better about myself already and as a couple we are feeling much closer to each other.”*

Patient V:

- **General Feedback:**

After our first session she said:

*“I still have so much to talk about and to ask ...but feel very excited about the sessions and I already feel much ‘lighter’ ...thank you! ...I need to talk about my emotions and hardship I went through during my breast cancer.”*

She said:

*“...I felt better after every session with you and just the opportunity to talk about the treatment and my experience of it made me feel ‘lighter’ and less abnormal.”*

She said that one skill she used a lot was the principle that she would be ‘different’. She would be different as a person, a mother and a wife, and when something new came up she would react to it differently than before.

*“...I remember this principle and consciously try to replace an old or inappropriate thought or behaviour with a ‘new’ behaviour and accepting it and making peace with it.”*

She also gave feedback about the time before the last session where she had to go through all her tests and scans, and although she was anxious and scared, she kept in mind that it was ‘normal’ which helped her to cope with and manage it and feeling good afterward when she got the good news that everything was good and she was still in remission. She said she felt so ‘proud’ of herself for handling herself emotionally better than before. She said that the opportunity to have

spoken about her child and ask all her questions about handling him was a very positive experience because:

*“...I didn’t know where else to talk about him, I had so many guilt feelings about him and me being sick, especially now that I am cancer free, I feel ashamed to still feel stressed about dying from cancer and I don’t feel to share this with anybody else ...but can now accept the reality that it is normal and realistic to be scared of our future because of my cancer and also not feel guilty about my feelings regarding my child and my cancer ...for me one of the biggest perks of going to therapy is speaking about everything and anything that you feel you cannot speak to anybody else without feeling being judged or being frowned upon.”*

Another feedback from her was the fact that after the sessions:

*“...I felt so ‘normal’ for hearing that other woman in my situation also feels the way I do and I am not the only one ...receiving information about all the unfamiliar things that was happening to me made me more relaxed and have put my mind to rest about things like my on-going tiredness and lack of energy and menopause, which I understood nothing of before the therapy.”*

She said that when she started with therapy:

*“...I was so depressed and anxious, but understand it much better now, I also feel much better, more in control of my own body and of my own thoughts and just all together lighter ...I feel positive about therapeutic sessions because it helped me and my husband and son a lot during the last part of my cancer journey...”*

She said because she felt so positive about therapy, she would like to continue with the sessions,

*“...Seeing you makes me feel comfortable and we already have a therapeutic relationship ...I would like to from time to time feel supported by a professional person and would like to express my feelings and possible questions or worries in a therapeutic environment ...I feel empowered by these sessions.”*

- **Relationship and Sexual Feedback:**

After the individual sex therapy session she said:

*“I feel very positive about the information about my sexual functioning and much ‘lighter’ about my whole sexuality as before I came in here today...”*

After the couple’s session she gave very positive feedback regarding her husband, who was very unapproachable and curt in the beginning of their mutual session, saying:

*“He has experienced the session rather positive and that after the session I could see a change in his behaviour ...we talk more to each other and he is making an effort to spend more time at home with me ...I feel more accepted and understood by him, although I know that there is still a long road ahead of us ...for the first time since my cancer, I feel that he is on board...”*

Even with our last session, which was nine months after the couple’s session, she said:

*“...We are functioning much better as a couple now, we talk more, do more things together and my husband is more attentive to me than before ...even sexually, and I can see a huge difference.*

She said:

*“...even if it is so long after our session my husband is still committed to his ‘new’ behaviour ...both of us still use the therapeutic guidelines from our mutual session and the fact that he is more understanding and supportive makes me feel much better in general.”*

## **7.5 PRESENTATION AND INTERPRETATION OF THE QUANTITATIVE RESULTS**

The results of the standardised questionnaires, the Female Sexual Functioning Index (FSFI) and the Hospital Anxiety and Depression Scale (HADS) will be discussed. These two questionnaires were included in the study for gathering and measuring data regarding sexual functioning, depression and anxiety from the five breast cancer patients. The questionnaires were given and explained to study

participants during their first official session where they took it home to complete. Using both qualitative and quantitative methods abled the researcher to compare what the patients genuinely experienced and was willing to verbalise during an open interview as opposed to what a “scientific” questionnaire reveals about the same topic.

### **7.5.1. HADS**

#### **7.5.1.1 The depression sub-scale**

From the interviews, *Patient I* said that she felt severely down and depressed at the time of her treatment, but became better after the end of the treatment and in her remission state. Her depression score on the HADS, which she filled in at the beginning of the study, (between the first and second session) was a 7 which was in the normal range. Her score reflected her current emotional state during the psychotherapeutic stage which was not as depressed as she felt during and just after her treatment. She was also, at the time of this study, on an anti-depressant.

*Patient II* never developed severe symptoms of depression during her treatment trajectory although she sometimes felt down and tearful and emotional, especially because of the tiredness during her chemotherapy. Her score on the HADS was a 4 on the depression side, which fell into the (low) normal scoring of 0 – 7 and fitted in with her mood at the beginning of her treatment.

*Patient III* experienced her cancer and cancer treatment from the beginning as very emotional, and was very tearful for most of the time during the earlier sessions. She was diagnosed with a major depression according to the DSM-5 criteria during our last session. Her score on the HADS, which she filled in in the beginning of the therapeutic process, was a 6 on the depression side, which fell into the normal range between 0 and 7. This was a true indication of her emotional status in the beginning of the sessions, although tearful and sad, she was not clinically depressed. There was a clear change from only feelings of depression in the beginning of the treatment regime, to the end where she presented with a full-scale major depression due to the cancer and cancer treatment.

*Patient IV:* Her score on the HADS which she filled in in the beginning of our sessions was 13 which was in the abnormal category and was a true reflection of her mood status when we started with the sessions. Although she presented with symptoms of depression from the beginning of our sessions, which was also the reason why she was referred, she was already on an anti-depressant and under treatment of a psychiatrist. During our therapeutic process, there was a need to assess her symptoms again for depression (according to the DSM-5 criteria) because her mood was spiralling down and mood became much worse.

*Patient V* was feeling depressed when she was referred to me by her oncologist. She was evaluated by the researcher in terms of her symptoms and was found presenting with all the DSM-5 symptoms of a Major Depression. In spite of her clinical diagnosis of depression, her score on the HADS on the depression side was only 6, not corresponding with her true symptoms and feelings of depression.

Out of the five patients, one patient's results of the HADS questionnaire, regarding the depression sub-scale, didn't correspond with her true clinical symptoms.

#### **7.5.1.2 Anxiety sub-scale**

Both *Patients II and III* tested within the normal range of anxiety on the HADS, which was not a completely true reflection of how they felt in terms of anxiety. They were both anxious enough to have complained about it and for me to feel that it must be addressed in therapy.

*Patient I* was diagnosed with, and treated for a general anxiety disorder by the time that we started with our sessions. The anti-depressant Ciprallex 20 mg was prescribed by her psychiatrist. Her score on the anxiety side of the HADS was 6, in line with how she felt when I started seeing her in therapy. She said that although she was still having her anxious moments, it was more under control with the medication and sessions with her psychiatrist.

*Patient IV* was from the beginning of our sessions both depressed and anxious and tested 13 on the anxiety side of the HADS which is in the abnormal range. This was representative of her anxiousness that she felt during the time of the test.

Although *Patient V* experienced high levels of anxiety during the beginning of the therapeutic process, her anxiety score was a 6 on the HADS which falls in the normal range, not indicating her symptoms of anxiety.

Three of the five cancer patients did not have representative anxiety scores on the HADS that agreed with their true feelings of anxiety. This made it clear for the researcher to ask about anxiety (and depression) and not just rely on tests and tests results, for it might not be a true indication of a patient's real experience of her mood.

### **7.5.2 The female sexual function index (FSFI)**

*Patient II:* Her score on the FSFI was 51.8 which indicated that she did not suffer from a female sexual dysfunction (a score  $\leq 26.55$  is classified as FSD), which corresponded with what she said during the sessions regarding her sexual functioning.

*Patient III* had previous sexual problems (before the breast cancer diagnosis) due to marital difficulties and physical conditions. Both her and her husband suffered from chronic diseases that were not under control. This patient has scored 19.6 with the FSFI scale, which fell in the range of female sexual dysfunction. This agreed with her sexual functioning at the time of the test and which she also experienced.

*Patient I* experienced and expressed overwhelming sexual changes during and after her cancer treatment. She attained a low score on the FSFI scale, less than 26.55, which indicated sexual dysfunction in all the areas of sexuality.

*Patient IV:* Her symptoms of depression overruled her sexual functioning and she didn't give a lot of thought prior to the therapy about her sexual functioning. Her score on the FSFI scale was very low, indicating sexual dysfunction in all the areas that was tested, and agreed with her lack of sexual interest or activity during the time of the study.

*Patient V:* although there were changes in the way her body reacted to sexual stimuli and also in the frequency of their sexual activities, she said during the



sessions that they do not experience problems in their sexual functioning. Because of her recent hysterectomy and sexual abstinence, we had agreed that she would fill in the questionnaire as how their sexual activities and her sexual functioning were before the hysterectomy. She scored a 33.1 which was well above any sexual dysfunction and which matched what she said about their sexual functioning.

The scores of the five cancer patients on The Female Sexual Function Index (FSFI) were in par with what the patients experienced and disclosed during the interviews.

## **7.6 SUMMARY**

The purpose with this study was to discover and learn more about the personal and intimate experiences of the breast cancer patients, not just through their own “lived” experiences, but also through their own “uncut” version of their stories. Since I was so closely involved with them because of our therapeutic sessions over a long period of time, and even per occasion with their life partners, I was able to encapsulate more insight and understanding of their cancer experiences and needs, as individuals, but also as part of a couple and family. I have learned that although there were mutual themes among their experiences, there was uniqueness in every one’s experience of her breast cancer. I feel humbled and honoured to have been allowed to be part of such a journey for my research study. I have listened and learned from each and every patient of mine and I have again experienced the true value of being passionate about my work. I feel I have a better understanding of the experiences of the breast cancer patient and even the biological side of breast cancer and all the new medical advances.

I have also compared some of the main themes, such as depression, anxiety and sexual functioning with structured questionnaires (quantitative methods) as a validity procedure and to be able to integrate, compare and triangulate the results.

In the following and final chapter I will discuss my findings and conclusions of the data and discuss the implications of the study and conclude the evidences of the study.

# CHAPTER VIII

## Discussion and Conclusions

In this chapter I will discuss the research findings of the study as well as the limitations and implications for practice and further research. The discussion will be divided in two sections, namely the biological- and psychological experience of the breast cancer patient and her need for psychological interventions and the implementing of psycho-therapeutic interventions.

### 8.1 DISCUSSION

The primary objective of the study was to explore in depth, the breast cancer patient's lived experience and unique insights of her cancer journey and her expectations for psycho-oncologic interventions. The in-depth understanding of the findings was developed using qualitative analytical procedures described in Chapter VI.

It was found that fewer qualitative case studies have been found to investigate the in-depth phenomena of the breast cancer experience, especially the quest for psycho-oncologic interventions (Edwards et al., 2008; Faller et al., 2013; Hersch et al., 2009). I have tried to fill this gap by using a methodology which allowed for a rich and in-depth perception to be heard through the voices of the five participants who had experienced the trauma of a diagnosis of breast cancer and breast cancer treatment.

#### 8.1.1 The biological and the psychological experiences of the breast cancer patients

It was evident during the therapeutic process that the five patients and (per occasion) their partners, were willing to share their emotional and sexual experiences by speaking openly and without prompting about it. It appeared that each of the five breast cancer patients was committed and interested in being part of the research study and my impression was that they were looking forward to each session and that the sessions were marked by a natural flow in the interaction between us.

- **The need to talk:**

The results of this research study indicated that regardless of the stage of the treatment or survivorship that the patients were in, they all had a prominent need to talk to a professional person about their emotional and sexual experiences regarding their breast cancer. All five patients experienced the news of their breast cancer diagnosis as traumatic and overwhelming. The three patients already finished with their treatment felt that they never had the opportunity to have worked through the initial trauma of the diagnosis before they were confronted with the “extended” trauma of the different treatment modalities and chronicity of the illness. These three patients disclosed that they did not know how to deal with the trauma of their diagnosis from the very beginning up to where they were when we started the sessions, leaving them feeling hopeless and out of control. The two patients that were undergoing their cancer treatments both expressed that they would never have known how to handle the stress of their diagnosis simultaneously with their “tough” treatments if it was not for the therapeutic sessions. This is evidence how important early on referencing to psychological services from the oncology team is (Kessler, 2014; Livneh, 2001; Swack, 2008). All five patients have clearly declared how glad they were for the opportunity to have spoken to me about everything, even things and experiences outside of the cancer regime, but especially over sensitive matters such as their deepest emotions, fears, dying and sexual issues.

- **Communication and relationship with the oncology team:**

It is evident from the findings of this study that all five patients confirmed that the communication between them and their oncology team (mainly their oncologists and surgeons) were unsatisfactory regarding sensitive matters as in their emotional- and sexual experiences and side-effects of their breast cancer. They perceive this lack of communication as negative, leaving them in a disposition to know what is happening to them and what they can expect of their future, leaving them unable to prepare for any emotional or sexual side-effects. Three of the five patients felt that their oncology team were not looking out for them or supported them on an emotional level. Apart from Patient IV, not one of the other patient’s oncologists or surgeons have suggested or referred them at any given time to a

psychologist or made any reference to conditions such as depression, anxiety or any form of sexual functioning regarding their cancer treatment. The two patients undergoing active treatment were very surprised that their sexuality would be compromised because of the treatment, not suspecting it at all. The other three patients “suffered” from sexual changes and challenges, but as one of them said “*I suffered in silence*”, they did not know what was happening and why, or even what could be done about it to improve it. All five of the patients were pleasantly surprised to have had the opportunity to speak about their sexual reactions, especially menopause and its influence on their bodies in a comfortable and professional environment. The three patients who were finished with their cancer treatment felt very strongly, that if they had better communication with their oncologists and received some information regarding their sexual functioning, they could have been saved a lot of unnecessary hardship, not just in themselves, but also in their relationships. All three felt that their unfamiliar and unexpected sexual and bodily changes (e.g. menopause) have contributed negatively to their emotional state of mind. According to Hewitt (2006) the oncology team can provide psychological resources proactively to cancer patients, including appropriate referrals. After completing their medical treatment, the three survivors reported that they had to learn about their psychological reactions and chronicity of the illness and support services on their own with no or little guidance from the medical personnel. It was noticeable during the course of the study that oncology teams did not discuss the psychological impact, such as mood disorders, or emotions or sexuality with their patients, leaving them completely in the dark regarding the bigger picture of cancer.

Although cancer is the first field of medicine where psycho-social factors have been taken seriously, looking at the results regarding the lack of emotional communication and support between the breast cancer patient and the medical team and the absence of a proper referring system to disciplines such as psychology, it is evident that the oncology team still operates predominantly from a bio-medical model when treating cancer (Clark, 2010; Venter, 2014). In spite of new paradigms, such as holistic- and humanistic-evidence based medicine and sufficient evidence that breast cancer has profound psychological and sexual effects on the breast cancer patient, it is still evident that the communication skills

and approach from the oncology medical team to accommodate these effects, are still lacking (Clark, 2010; Fallowfield & Jenkins, 2015; Ghaemi, 2009; Mok et al., 2008; Nicolas, 2013; Richards et al., 2014; Spiegel, 2008; Vetere, 2007). I have learned from the conversations from the study patients, that the medical team often does not have the proper knowledge to distinguish between the qualification and practises of social services and psychologists or clinical psychologists (that was discussed in Chapter I).

- **Depression and anxiety:**

Although there was no indication of a major depression or anxiety disorder when the study began, the two patients that was undergoing their cancer treatment had the opportunity to, throughout the cancer treatment and psychotherapeutic sessions, to talk about their mood and what they were experiencing. They received information during our sessions of what depression and anxiety are, especially what anticipation anxiety is and what symptoms to look out for, also as to what they could do should they develop a mood disorder. Patient III has developed depression during the later stage of her cancer treatment and was noticed by me and after an evaluation (checking of the DSM-5 criteria) she was diagnosed with a major depression and was referred to the oncologist for an anti-depressant. It is my opinion that if this patient was not part of the study, the diagnosis of a major depression would have been neglected and she would not have undergone psychological treatment at all. Sadly this was the route of the other three participants (Patients I, IV and V) who had developed symptoms of depression and anxiety during and after their cancer treatment, but was not treated for these conditions, nor was it explained to them or acknowledged in any form from the oncology team. This has resulted in an underdiagnosed and undertreated condition or conditions which had incapacitated their complete functioning level, without any knowledge about how to overcome that or to proceed from there on. Because depression and anxiety are both treatable conditions, it is an unnecessary stress that the breast cancer patient or survivor must endure. These results was highlighted by a study done by Thompson and colleagues (2013) where they have found that depression in this cancer population is often under

depression and anxiety through early diagnosis is therefore a worthwhile goal (Hill et al., 2010; Meier, 2010). Pre-morbid psychiatric history is a well-known risk factor in developing depression during and after breast cancer which was confirmed through the diagnosis of Patients I and IV. It was evident during the study that mood disorders played a big role during the treatment and afterwards in the lives of the breast cancer patient.

Apart from depression and anxiety, all five patients experienced anticipation anxiety, without understanding it or knowing how to handle it, especially the two patients who were still busy with their treatment. They experienced severe anticipation anxiety before their breast surgery with incapacitated results on their current functioning and emotional status, influencing to a large extent their quality of life. The three patients finished with their treatment, also experienced anticipation anxiety regarding the regular blood tests, scans and other tests and follow-up appointments with their oncologists or other cancer specialists.

During the sessions I experienced that the chronicity of the follow-ups and continuous angst regarding the results and their fear of recurrence, left them with many questions as how to deal with such on-going phenomena. Sadly for these three survivors, they had, not up to the sessions, had any relief in answering these questions.

- **Other side-effects and emotions worth taking about:**

The current study has found guilt feelings as another prominent emotion that breast cancer patients endure during their cancer treatment and are not always willing to talk about it with just anybody. The five study patients had all experienced guilt feelings to some degree during and after their cancer treatment for not being able to full-fill their roles as a mother or wife, causing them to experience feelings of hopelessness and worthlessness. The two patients who were still busy with their treatment had acute guilt feelings because they were so busy with their cancer treatment and side-effects and so were often tired that they were not there for their husbands regarding the household chores and care. It was also clear from the results of the study that the two mothers with young children had more intense guilt feelings regarding their children, especially the fact that

they were not as involved in their children's lives as before the cancer, especially during their chemotherapies. Both felt that they had missed out on some aspects of their children's lives during the time of their treatment, making them feel guilty even after the treatment had stopped.

Guilt feelings also played a big part when it came to fear of death, which in this study was a central emotion. All five patients went through a period of intense fear of dying after they heard the diagnosis of their breast cancer. Patients II, III and IV made peace with their diagnosis and death after the initial shock of the diagnosis wore off, while Patients I and V kept on having fearful thoughts about dying and leaving their young children growing up without a mother. Apart from their fear of dying these two patients felt guilty about feeling scared of dying while their prognosis of their breast cancer was actually good and they were in remission, feeling that they might "temp fate" by being scared of dying. Again, while all five patients were scared of recurrence of their cancer, it was the two patients with younger children, who had severe anxiety regarding recurrence of the cancer and dying, leaving their children behind. Literature confirmed that young woman diagnosed with breast cancer are more prone to develop depression (Gnerlich et al., 2009; Hussein et al., 2013; Meier, 2010; Raque-Bogdan et al., 2015) and experience fear of cancer recurrence more than that of older women, mainly because of their children (Lebel et al., 2013). Guilt feelings and fear of dying were also a private matter to all of these patients not wanting to talk to anybody about it, feeling that people won't necessarily understand it and also not wanting to "burden" their families with such negative and destructive feelings. They were glad for the opportunity to have been able to talk to me about it without feeling ashamed and understood it better within the cancer framework.

Apart from outspoken mood experiences, this study highlighted the severe effects that chemotherapy has on the patient's body and emotions especially fatigue. This was the one symptom that everyone in the study relentlessly experienced with far-reaching consequences on every level of their functioning, biologically, psychologically and sexually. This was one of the topics that were discussed the most and the most intensely by all five patients in almost every session over the whole period of the therapeutic process. This is consistent with literature stating

that fatigue is one of the biggest post-treatment problems in breast cancer patients, and although it is usually acute, a large percentage of patients experience persistent fatigue after completion of treatment, even when in complete remission (Berger et al., 2015; Dimeo, 2008; Fallowfield & Jenkins, 2015). Fatigue is a good example of a physical cancer treatment related side effect that effects a person's emotions directly, e.g. all five patients felt guilty because of their severe fatigue and the incapacity on their overall functioning and the contribution to their feelings of depression and helplessness. It was also evident in this study, that when a patient understands a symptom or side-effect and is able to put it in a realistic framework, (e.g. fatigue is a common symptom of chemotherapy, it can continue after treatment, but there are skills to work around it), it becomes less traumatic and more bearable for the patient.

- **Family: marriage and children and social support:**

The importance of support from their family and friends were confirmed by all five patients, with emphasis on their partners and grown-up children, for providing them with much needed emotional support. Patient III had problems before the cancer with family relationships and marital problems and it was very clear to me that it had influenced her in a very negative way. It was evident to me that relationship problems that was present before a diagnosis, don't just go away because of the cancer diagnosis, but in fact can worsen during the hardship of the cancer treatment. I observed that a lack of support from one's husband and/or children can have a negative impact on a patient's ability to adhere to her treatment and adaptation to the treatment process. Through the therapeutic process the relationship with this patient's husband and children had improved ending in a much more positive note by the end of our sessions. It is my opinion that if this patient did not have the opportunity to have gone through the therapeutic process to help her through her cancer, she would not have the time or the knowledge to have sorted her relationship problems out on her own because of the demands of the cancer treatment. Patients I, II and III had good spousal relationships before their diagnosis and it continued to be good afterwards. All of them feeling that the cancer had in fact drew them closer to each other. Patient V had a very good relationship with her husband before the cancer,



but it changed during her treatment and afterwards because of a lack of support from him and an inability to understand her cancer and her emotional needs. This has left the patient with a lot of resentment towards her husband and was also one of the reasons that she developed serious mood symptoms and marital problems after the completion of her treatment, asking for a referral to see a psychologist. These findings indicate that emotional support and communication from the patient's spouse are important aspects that enrich a breast cancer patient's ability to go through the cancer treatment and adaptation to the illness and survivorship, but that they often need help dealing with problematic relationships.

- **Work and financial matters:**

The results of the current study showed the impact that breast cancer can have on the financial status of a cancer patient. Two of the three patients who underwent cancer treatment as private patients felt a lot of pressure to go to work during their treatments, especially the chemotherapy, regardless of how sick they felt, as not to jeopardise their jobs and maybe losing their income and then not being able to pay for their medical aids or bills. One of the state patients had to resign from her job due to the physical pressure of her type of work, losing her income, which was another burden on her and her family that they had to endure together with the stress of the cancer and cancer treatment. It was evident from the results of the study that work and the identity that a career provides plays a very important role especially during the treatment phase. The three patients, who were finished with their treatment, talked the most about their jobs and job-related challenges. (One patient took of one year while busy with her chemo). One of the biggest challenges that they experienced was to be able to get up and go into the offices every day during their chemotherapy treatments, for that is when they felt the worst biologically, e.g. suffering from symptoms such as fatigue and chemo-fog. Apart from the negative experiences regarding chemotherapy and work, all three working patients have agreed that their work helped them to have coped during their treatment (and after) in providing them with collegial support, which they all experienced very positively. Going to work also helped them to have felt "very normal" by doing "normal" things, but the biggest advantage was the fact that they felt it helped them to focus away from the cancer experience.

- **The topic of sex:**

The most common complaint amongst the five study patients regarding the influence of the cancer treatment on their sexuality was the fact that sex as a topic was never raised by their oncology team. The only mention that was made, but not necessarily discussed, was that of menopause as a side-effect of the chemo- and hormone therapy. The two patients still busy with their treatment didn't experience any sexual changes yet, but were thankful for the opportunity to have talked about possible changes and challenges regarding their sexuality that they could expect and prepare themselves for it. They both said that they found it extremely liberating to have spoken to a neutral and professional person about sex and sexuality for they were not used to speak about sex to anybody. The therapist has found that by spontaneously talking about sex and using examples of other breast cancer patients and their sexual experiences during their treatments, has enabled them to engage in comfortable sexual conversations, to the extent that Patient III has also revealed her sexual problems from before the cancer diagnosis. The results from the study regarding the three patients who were finished with their treatments, was in line with recent literature that sexual problems and body-image changes are very prominent cancer treatment side-effects and can last for many years after successful treatment, but are not often accommodated by the oncology team (Emilee et al., 2011; Kuo et al., 2008; Park et al., 2009; Reece et al., 2010; Speer et al., 2005; Taylor et al., 2011; Usher et al., 2013).

It was evident from the study that the three patients in remission experienced severe changes in their body image, especially because of the changes in their breasts and body weight, and their active sexual functioning, as in their lack of libido and menopausal symptoms. All three patients said explicitly that although menopause was explained to them, the suddenness of it and the unexpectedness caught them unprepared, leaving them very vulnerable regarding their functioning as a sexual being. Results concerning the patient's need to talk about, and actively do something about their sexual challenges, showed the importance of engaging your cancer patients in sexual conversations and as the professional person to lead the way in this line of conversations. Talking about the symptoms of menopause was also a topic that was very prominent during the study and the

effects that it has on self-image and emotional functioning of the breast cancer patient. It was evident in the study that breast cancer patients, because of their sexual challenges, wanted their partners to be part of their psycho-therapeutic process concerning their sexual changes, implicating that the therapist must make provision for inviting the partner to a session or some of the sessions. It was evident for me, regarding the sexual topic, that age did not play a part in the eagerness of the patients to discuss their sex lives and to learn new skills to improve the quality of it and that all five wanted to engage in good and healthy sexual activities.

The results of the study with regards to the psychological and sexual side-effects from breast cancer treatments suggest that the quality of life of this population can be seriously compromised by it. By not recognising and accommodating these elements during the treatment by the oncology team can cause this population to suffer unnecessary psychologically in addition to an illness that has already affected and challenged them in a biological way.

### **8.1.2 The psycho-oncologic interventions**

One of the most prominent observations that I have made during the study was the willingness and eagerness of the participants to engage in a psychotherapeutic process to talk about, and understand and manage the effect of their breast cancer treatment better and to “learn” to enhance their overall quality of life. It was evident that by engaging the patients in conversations about sensitive matters through spontaneously talking about what other breast cancer patients experience, even if they did not ask or mention specific topics, made them comfortable to discuss anything that they had issues with.

Results from this study have shown that some people do not know what a psychologist or clinical psychologist does or his/her role in the treatment process of cancer. This was clear with Patients II and III, the state patients, but also to a lesser degree with the private practise patients, but once they have participated in, and understood the therapeutic process and experienced their own benefits during the psycho-therapeutic sessions with a clinical psychologist, they agreed that a psychologist can play an important and necessary role during the cancer treatment process. I realised that there is still a long way to go both in government

funded hospitals and in the private practice to introduce services like psychology when treating medical conditions, such as cancer. Patients I, IV and V, who were more familiar with what a psychologist do, were not introduced to or recommended the services of a psychologist during their treatment phase or even after their treatment, (apart from Patient IV), and was left to their own devices to deal with their psychological problems. All three patients revealed during therapy that they thought that they would have benefited from this service if they knew about it or could afford it, but it was not an option for them during their treatment and they didn't have enough knowledge to realise the significance of participating in therapy during their active cancer treatment.

Another prominent finding during this study regarding psychological intervention was the need of the patients to talk about their cancer experience and to share their emotions and fears and anxieties with a professional person who understood their hardship without feeling judged or feeling guilty talking about certain sensitive subjects. The importance of normalizing emotions and thoughts and experiences was very evident during the therapeutic sessions as was the patient's relief when they realised that other patients in their situation or condition, have the same experiences and concerns and issues. I experienced that a big part of the psychological "healing" process of the breast cancer patients was grounded in emotional expressing and the understanding of their own emotional experiences and for the therapist to communicate this understanding to them and putting their experiences in the framework of cancer and cancer treatment. It is extremely important for the patient to feel "normal" and to be perceived by other people as "normal" while going through a tough and unfamiliar and overwhelming period.

Another therapeutic intervention that was received in a very positive light by the study patients was psycho-education. The mere giving of information and knowledge about concerns and subjects that the patients don't have previous experience of made them feel relieved and knowledgeable about the matters and more in control of their bodies and unfamiliar situation. This observation agrees with my belief that "knowledge gives power" to any person in any given situation. I found that the topics the breast cancer patients most needed knowledge about was the specific side-effects of the cancer treatment, especially chemotherapy

such as fatigue and memory problems and the psychological and sexual side-effects. Depression and anxiety were also two topics that needed a lot of explanation, as was menopause and premature menopause with their accompanied symptoms. In terms of sex therapy and sexual conversations all five patients had indicated their gratitude for being allowed to talk about it (the forbidden subject), but also learned new skills regarding their sexuality. I have observed a lot of relieve from the patients for being able to feel sexually more informed and liberated and “normal” in their new breast cancer status quo. It was also evident that learning to accept and improve their self-image and body-image made a huge difference in their overall sexual functioning and perceptions of themselves as sexual beings, despite their breast cancer. Again it was noticed that without engaging in formal sex therapy, by just giving the patient room to talk about sex and providing necessary and basic information, it can already solve some of the problems and improve their sex lives.

This study highlighted the applicability of short term cognitive- and behavioural techniques when working with breast cancer patients, treating both psychological and sexual issues. By teaching breast cancer patients to be consciously aware of their thoughts and behaviours regarding their cancer experience and the ability to change or amend these thoughts and behaviours, can help them to accept and cope better with their situation and improve the overall quality of their lives. By teaching them coping skills, it provides them with a better change to adapt to and make peace with their new and chronic situation on a psychological healthier manner. Making use of cognitive and behaviour techniques in applying sex therapy was also observed in a positive light. It is my opinion that all five patients found cognitive and behavioural techniques easily understandable and practical, which could be seen from their feedback regarding interventions which they could implemented with success. This is consistent with findings in other studies regarding breast cancer and cognitive- and behavioural therapy (Anderson, 1992; Hummel et al., 2015; Mullan, 1985; Savard et al., 2005; Ussher et al., 2013).

After the couple’s session, the feedback from the four patients (which husbands participate in one sex therapy session) was very good indicating the need to involve the significant other of the breast cancer patient and to acknowledge their

need to express their own experience and emotions of their partner's cancer and their need for information regarding emotional support and sexual functioning. The response from the partners (through feedback of the patients) was that the sexual input during the session was very valuable for them, as was the general information regarding breast cancer and the treatment. A big advantage for both the partners and the patients was the knowledge of what to expect further in the future and the opportunity it was giving them to prepare for it and learn skills to handle it.

It was noticed from the feedback of the patients that they experienced the practical "advise" regarding certain matters as very helpful and positive. Specific examples given by the patients were the time management skills with their fatigue, the changing of their short- and long term goals to more reachable goals, and incorporating new sexual behaviour, with specific mention to their self-image and over all sexuality.

### **8.1.3 Implications of the study: strengths and limitations of the research**

#### **8.1.3.1 Strengths**

The strengths of the research appear to be as follows:

- Including patients from different ages and different stages of the cancer continuum (active treatment and survivorship) can be seen as a strength of the study for it provided in-depth information on the experiences of different age groups and different stages of breast cancer.
- Including both private patients and state patients can be seen as possible strength of the study, for it enables the reader to experience both worlds of the breast cancer patient.
- The qualitative approach of this study has enabled the voices of the breast cancer patients and survivors in terms of their experiences of the cancer and needs from the oncology team regarding psychological interventions, to be heard from a perspective of real "lived" experience.

- Because there is so little qualitative research done on psycho-oncologic interventions with breast cancer patients, especially on the sexual subject, this research enables formulation of new insights in a field that is ripe for studies of psychological interventions.
- The fact that the researcher was also the therapist can be seen as an advantage of the study since I had first-hand experienced the real “lived” worlds of the patients (and partners) but also their reactions to and implementation of the therapeutic interventions.
- The feedback session (the last therapeutic session) that was held with the five patients and which has provided the reader with rich in-depth information in their own words regarding the therapeutic process, has confirmed the trustworthiness and dependability of the study.
- The combination between the quantitative questionnaires and qualitative methods had complimented each other in the sense that the questionnaires had provided the confirmation that depression, anxiety and sexual pathologies are real in the cancer world, and it can be measured and compared with the information from the patients self.

### **8.1.3.2 Limitations**

This study was designed to address the gap in literature concerning the psychological and sexual experience and psycho-intervention needs of the breast cancer patient and breast cancer survivor, but there were several limitations that should be considered when examining the research findings.

- One of the limitations of this study was the small sample size, which can be criticized for not being able to generalize, however small samples are typical of qualitative research and the aim of this study was not to statistically generalise results, but to provide a rich and comprehensive presentation of the experiences and perceptions of the breast cancer patient.



- Another possible limitation of this study is that the participants and the researcher shared a cultural context which makes the results not applicable to persons from different cultures and languages.
- I have tried to be aware of my own suppositions because of my longstanding and enthusiastic interest in breast cancer and have tried to avoid bias in my interpretation of the information and experiences of the breast cancer patient. I also understand that it is impossible that these components do not influence the interpretation to some extent. Although this limitation is part of qualitative studies, I have made an effort to minimize this through honesty and transparency regarding the ideas and beliefs that was brought to the interpretation of the data.

#### **8.1.4 Implications and recommendations for research and practice**

##### **8.1.4.1 Further Research**

- Being diagnosed with breast cancer causes major psychological distress, but recent findings indicate that there is, to date, a lack of convincing evidence of the implementation and benefit of specific psycho-oncologic interventions to improve the quality of life of the breast cancer patient during and after treatment (Faller et al., 2013; Galway et al., 2012; Hersch, 2009).
- The uniqueness of the one-on-one interaction with the five breast cancer patients and the in-depth feedback regarding their cancer experience and therapy suggested that the best way of further research in this field may be in a qualitative direction.
- It is my suggestion that a larger sample size and a more diverse group of breast cancer patients might increase the data of the breast cancer patients' experiences and needs for further psychological interventions. It might be useful to work with the major cancer research hospitals as a referral system for potential participants.
- Clark (2010) claimed that although there is sufficient evidence for the effectiveness of psychological interventions in lessening distress and assisting psychosocial adjustment for breast cancer patients, there remains



much work to be done in this area. According to Clark there is a need for advocates in this field to “sell” the idea of psycho-oncology and participating in research and sharing their experiences to policy-makers and health providers to implement evidence-based and compassionate care beyond the trial phase.

- The researcher suggested more research to be conducted on the matter of communication patterns and relationships between the oncology staff and the cancer patient to accommodate and incorporate the more sensitive subjects of breast cancer and to support the cancer patient accordingly.

**Clinical Practise:**

Regarding the results of the study, I suggest a number of practical implications for improving the quality of lives of breast cancer patients and survivors and improving overall cancer care: I will distinguish in Table 8.1 between the practical implications and guidelines for the oncology medical team and for the psychologists working with the cancer population.

**Table 8.1: Clinical implications for both the oncology team and once-psychologists.**

<b>ONCOLOGIC- AND MEDICAL TEAMS</b>	<b>PSYCHOLOGISTS AND PSYCHOLOGIC SERVICES</b>
<p>Oncology healthcare professionals need to provide more than just a biologically based treatment plan through understanding and incorporating the breast cancer patients unique perceptions and needs regarding healthcare if treatment outcomes and quality of life are to be improved in the future for a rapid growing cancer population.</p>	<p>Tertiary education institutions who are responsible for the education of psychologists in South Africa, must integrate, at a post degree level, extra training to include the knowledge and treatment of cancer patients. Because cancer care is a highly specialist discipline involving the medical, psychological and sexual elements of cancer, psycho-oncology must be regarded as a specialist field and the</p>

<p>In practise it will mean that the oncologist and surgeon will have to accept the emotional and sexual side of breast cancer and address the matters with their patients during their consultations by providing opportunities to talk about sensitive matters.</p> <p>This study found a lack of emotional relationships and communication between the breast cancer patients and the oncologists and surgeons. It is important for the medical team to have proper communication skills regarding sensitive matters to enhance the cancer patient's quality of life and I suggest efforts to develop communication skills during the studies of medical students in order for them to deal with emotional and sensitive situations in an emphatic manner.</p> <p>The oncology–medical team must give recognition to and provide for a multi-disciplinary team to involve all the biological and psychological elements of breast cancer treatment. The current study showed a need to move towards a bio-psychosocial approach in treating the breast cancer patient with cooperation and communication among multi-professional team members.</p> <p>Because the psychological aspects of</p>	<p>education must be on par with that.</p> <p>Psychologists, working in the field of oncology, should advocate very strongly their services and knowledge in the field and how they can contribute to the treatment of breast cancer patients as part of multi-disciplinary team. They can also engage the medical and oncology specialists in a training capacity to acknowledge and integrate the psychological elements of breast cancer in their practise and develop communication skills to understand their patient better.</p> <p>In terms of sex therapy, specific individual interventions should be developed and implemented by onco-psychologists who specialize in sex therapy to help breast cancer patients to understand and adjust to their altered sexual needs and sexual (body) self-esteem. Programs like this should include specific sexual communication skills with their partners, and elements like the Five A Comprehensive Model (as discussed I 5.4.1) and Masters and Johnson's Model of Sensate Focusing, and cognitive-behavioural techniques.</p> <p>Health professionals, both the oncologist and the psychologist, must integrate patient sexuality and intimacy</p>
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<p>cancer and cancer treatment can be so overwhelming as seen in this study and being supported in both older and more recent literature, it is time for the healthcare professionals to suggest to and encourage their cancer patients to involve in psychotherapy during cancer treatment and thereafter. It is saddened to see that in spite of the traumatic experience of breast cancer and the time consuming and overwhelming treatments and side-effects, psychological interventions are still not a priority for most of the medical team.</p> <p>I further suggest that oncology-medial teams familiarise themselves with the different psycho-social services that are available, such as clinical psychologists, counselling psychologists and social workers.</p>	<p>into routine palliative assessments so that every patient is given the opportunity to discover these matters and talk about it freely (Hordern &amp; Currow, 2003; Hummel, et al., 2015; Park, et al., 2009). By participating in sex therapy from an early start, the breast cancer patient can continue to feel sexually attractive and functional and will be able to sustain and conserve better courage and self-esteem throughout this process.</p> <p>Because depression and anxiety are the most common psychiatric disorders in the breast cancer population, the onco- psychologists working with breast cancer patients should make provision for evaluating and treating these conditions with specific techniques such as cognitive-behavioural therapy in combination with pharmacology.</p> <p>It is important for the onco-psychologist when developing individual interventions, to make sure that it designed to accommodate personal characteristics and age, as well as the type of cancer and treatment stage to enhance the overall quality of life of the cancer patient (Taylor, et al., 2011).</p>
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Private Practises and State funded hospitals:

There is a large need and opportunity for the oncology team to provide the breast cancer patient with psychological resources, such as either the services of a psychologist or appropriate referrals to a psychologist, both during the active treatment and at the point of treatment completion (Hewitt, et al. 2006; Stanton, 2012). But because of financial restraint, the development and implementation of accessible psychological interventions are crucial, both in government stated hospitals and private practises to enable the breast cancer patients to acquire psychological assistance to contribute to their overall mental health and adherence to their medical treatment.

The oncology medical team must be aware of the big possibility of depression and anxiety being part of the side-effects of cancer and cancer treatment and should make provision for evaluating and treating these conditions. If they are not equipped to do so, acknowledge it and then referred the patient for psychiatric/psychological support and intervention.

Improving cancer patients' access to psychosocial care remains a critical issue. Many patients who could benefit from psychosocial care do not receive the help they need. Barriers for this lack of service providing include under-recognition of the need for psychosocial care by the primary oncology team and, even when recognized, the lack of professionals available in many communities to provide psychosocial care to cancer patients (Jacobsen, & Jim, 2008).

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# APPENDIX A: Participant Interview Questions

## Participant Interview Questions

The principal interview questions:

- Tell me how you felt when you heard that you have breast cancer.
- What was your emotional reaction just after the diagnosis?
- How did you feel about the surgery?
- Did you feel the need to speak to a psychologist about the cancer diagnosis and the proposed surgery while in hospital? Was it suggested by the surgeon?
- Tell me about your experience during the chemotherapy.
- How was your emotional reaction(s) to the chemo? Did you at any stage feel depressed or anxious?
- Were the emotional side effects like depression and anxiety well explained to you by the oncologist?
- Did the oncology team attend to your depression and/or anxiety and was there open communication about this?
- Did you at any time of your life (before the diagnoses of cancer) suffered from Depression or Anxiety and where you ever treated for that?
- How did the chemo affect your family life and your work?
- Tell me about the Radiation therapy.
- Where in the trajectory (in what stage) of the treatment did you feel the most emotional?
- Do you experience any sexual problems because of the cancer? Have you ever had sexual problems before? (If the interview is before treatment – just after the diagnoses – the question would be – do think the cancer and treatment will affect you sexual life?)
- How did the chemo affect your sex life?
- How did the cancer/treatment affect you self-image and sexuality?
- Do you (and your partner) understand the side-effects of the hormone treatment (if you received any) and the effect on of that your body and sex life.
- Do you think it is necessary for a professional psychologist to explain the changes to you and your partner?

- Did you feel comfortable to have spoken to your oncology team about your sexual functioning? And did they volunteer any information about the changes in you sex life?
- (If the patient is in remission/finished with treatment). How do you handle cancer as a chronic illness?
- Looking back now would it have helped if you and/or your family could have spoken to a psychologist immediately after the diagnosis and before the surgery or chemo?
- Do you think it would have helped to have spoken to a psychologist about understanding your feelings? And to have involved the children and husband in a session to understand the whole process of cancer and treatment?

# **APPENDIX B: Informed consent form**

## **INFORMED CONSENT FORM**

### **SEX THERAPY AND PSYCHOTHERAPY AS PART OF A HOLISTIC PSYCHO ONCOLOGY TREATMENT PLAN FOR BREAST CANCER PATIENTS**

Dear Breast Cancer Survivor/Patient,

According to the latest statistics, breast cancer is the number one cancer amongst women in South Africa (one in every 31) but who has the highest survival rate (95%) when detected early. Five percent of these cancer survivors are younger than 35 years of age and predominantly premenopausal which comprise a special subgroup with unique concerns regarding early menopause, sexuality, infertility and fertility preservation. Breast cancer is clearly an important women's health issue.

Most breast cancer patients receive multi-modality therapy including surgery, (lumpectomy or mastectomy), chemotherapy, radiology and hormonal therapy, which cure the disease or prolong life, but the long term side effects of these treatments can significantly impact the quality of a patient's life, including sexual functioning.

This research forms part of my Doctoral study in psychology at the University of South Africa (UNISA). As a breast cancer survivor or patient I invite you to form part of the study that will investigate sex therapy and psychotherapy as part of a holistic psycho oncology treatment plan for breast cancer patients and to serve as a guideline for oncologist to understand the cancer patient better and to know how and when to refer his/her patient for onco/psychotherapy.

The study will involve an in depth interview by myself for an hour or 90 minutes at the hospital's oncology department and two questionnaires (a sexual questionnaire and a questionnaire regarding Depression and Anxiety). Depending on the outcome of the interview and questionnaires we will plan therapy sessions (the number of the sessions will be decided upon the therapeutic goals and practical time) and can be individual or as a couple, also at the hospital without

any costs. After the therapy sessions you will again be interviewed by me to determine the outcome of the sessions.

The benefit of the study lies in the information and knowledge that can aid breast cancer survivors and their oncologists in the long-term. The risk of your participation is limited but you may experience some distress as you answer the questionnaires and during the interviews due to the sensitive nature of sex therapy and psychotherapy.

All information will be kept confidential (participant files will be kept in a locked filing cabinet with no access to any other party than the researcher). Nothing will be made public with any identifiable information and reports will not have individual information. Only the researcher will know your identity and will keep this in the strictest confidence.

**Your participation is voluntary and you will be free to withdraw from the study at any time.** Your participation in this research will in no manner influence your medical treatment in any negative way.

Please feel free to contact me on 0829295699 if you have any queries or my study promoter Dr Madri Jansen van Rensburg (Tel: 082 403 5758) regarding any questions or comments.

# APPENDIX C: Consent form

## CONSENT FORM

I (name of patient) . . . . . hereby agree to participate in this research regarding emotional functioning (depression and anxiety), sexual functioning and psychotherapy after being diagnosed with breast cancer, before, during or after the cancer treatment. I also agree that my Oncologist can give my name and contact numbers to the researcher and refer me as a patient and I agree that my medical information can be given to the researcher/clinical psychologist (Vanessa Marais) doing this study.

I understand that I am participating freely and without being forced in any way to do so. I also understand that I can stop this interview or participation in the study at any point should I not want to continue and that this decision will not in any way affect me negatively.

The purpose of the study has been explained to me and I understand what is expected of my participation. I understand that this is a research project and that breast cancer patients, other cancer patients, oncologists and psychologists can benefit from this in the future.

I understand that there is psychotherapy and sex therapy involved and I understand the concept of the therapies as explained to me by the researcher. I also understand that the therapy will be done by a clinical psychologist without any costs.

I understand that this consent form will not be linked to the questionnaire, and that my answers will remain confidential and that the therapist – patient confidentiality as well as the doctor-patient confidentiality with my oncologist, will not be compromised under any circumstances. I also understand that my identity will be confidential.

Signature of Participant

Date

## APPENDIX D: Ethical clearance

Ethical Clearance for M/D students: Research on human participants

The Ethics Committee of the Department of Psychology at Unisa has evaluated this research proposal for a Higher Degree in Psychology in light of appropriate ethical requirements, with special reference to the requirements of the Code of Conduct for Psychologists of the HPCSA and the Unisa Policy on Research Ethics.

Student Name: Vanessa Marais. Student no. 53315049

Supervisor Dr. Madri Jansen van Rensburg Affiliation: Unisa / external

Title of project:

Sex therapy and psychotherapy as part of a holistic psycho-oncology treatment plan for breast cancer patients

The proposal was evaluated for adherence to appropriate ethical standards as required by the Psychology Department of Unisa. The application was approved by the Ethics Committee of the Department of Psychology on the understanding that –

- Because of the sensitivity of the information being sought and the fact that the participants come from a vulnerable population, it is required that ethical principles related to informed consent, anonymity, confidentiality and the right of participants to withdraw should be strictly enforced;
- Clearance is to be obtained from the hospitals from where the participants are to be drawn, and all conditions and procedures regarding access to patients for research purposes that may be required by these institutions are to be met;



If any further counseling is required in some cases, the participants will be referred to appropriate counseling services.

Signed:

Date: 10 February 2015

Prof P Kruger

A handwritten signature in brown ink, appearing to read 'P. Kruger', with a diagonal slash through the bottom of the name.

[ For the Ethics Committee ] [ Department of Psychology, Unisa ]

Bestpfe.com

# APPENDIX E: Institutional Clearance



TYGERBERG HOSPITAL  
REFERENCE: **Research Projects**  
ENQUIRIES: **Dr GG Marinus**  
TELEPHONE: **021 938 5752**

Ethics Reference: PERC 15012

**TITLE: Sex therapy and psychotherapy as part of a holistic psycho-oncology treatment plan for breast cancer patients.**

Dear Vanessa Marais

**PERMISION TO CONDUCT YOUR RESEARCH AT TYGERBERG HOSPITAL.**

In accordance with the Provincial Research Policy and Tygerberg Hospital Notice No 40/2009, permission is hereby granted for you to conduct the above-mentioned research here at Tygerberg Hospital.

A handwritten signature in black ink, consisting of a large, stylized 'D' followed by a horizontal line extending to the right.

**DR D ERASMUS**  
**CHIEF EXECUTIVE OFFICE**

**Date:** 7 December 2015

Administration Building, Francie van Zijl Avenue, Parow, 7500  
tel: +27 21 938-6267 fax: +27 21 938-4890

Private Bag X3, Tygerberg, 7505  
[www.capegateway.gov.za](http://www.capegateway.gov.za)

## APPENDIX F: Patient interviews

### PATIENT I

This patient was originally my Pilot Study patient but I decided to include her as one of my five sample patients because of her informative and insightful information and the whole perceptive therapeutic process that we had had, including the sex therapy. I knew about her when I started with the study and because of the fact that she was working in the medical field and had a strong understanding of psychology I thought she would contribute positively to the study. I contacted her telephonically and explained the study in short, asking whether she would consider to participate. She was very willing and enthusiastic to take part and to share her experiences of her breast cancer for the chance of helping other breast cancer patients through their process. Throughout the whole initial process of interviewing and therapy with her, I learned a lot about the type of questions that I had to ask and when to ask them. I realised that some of the questions that I had asked in the interview had already been answered in the demographic form. I decided to change from a more formal way of conducting the interviews to a more unstructured and therapeutic manner, giving the patient more autonomy to reveal appropriate and rich information and sharing her living experiences of the cancer. I also learned how to switch from asking (interview) questions to therapeutic inputs simultaneously and, given the limited time frame of the study, it worked out very well for both the patients and interviewer for it was beneficial to both. This was the only patient that I had scheduled interview appointments with. This was apart from the therapeutic sessions. With the other four patients I immediately started with the therapeutic process which included the interview questions and obtaining information.

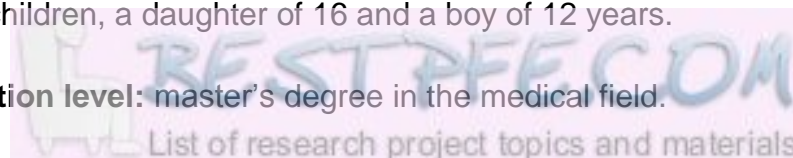
### DEMOGRAPHIC INFORMATION.

**Age:** 47 years

**Marital status:** married.

**Children:** two children, a daughter of 16 and a boy of 12 years.

**Highest education level:** master's degree in the medical field.



**Occupation:** practise in the medical field, working full time.

**Diagnosis:** Stage II Breast Cancer.

**Date of diagnosis:** October 2013.

**Surgery:** lumpectomy. (October 2013).

**Breast reconstruction:** completed.

**Treatment:**

*Radiation:* thirty two sessions – the last date was June 2014

*Chemotherapy:* “Red Devil” – four sessions and other chemotherapy – four sessions - eight in total. Chemo over a period of six months - the last date was on April 2014.

*Hormonal therapy:* Neophedan (Tamoxifen).

*Anti-depressant:* Cipralex 20 mg for the last two years.

*Psychiatric treatment history:* She was treated for depression before the diagnosis of breast cancer.

**Diagnoses**

The patient was diagnosed with Stage II Breast Cancer and had had a lumpectomy and removal of all the axillary lymph nodes in October 2013. She had had eight sessions of chemotherapy and thirty-two radiation sessions all ending in June 2014. Because she had completed her treatment so long ago and she had not been referred by an oncologist, I did not have access to her medical file. All the information was given by the patient herself.

**Treatment plan**

After the lumpectomy and removal of the axillary lymph nodes, the patient had started with eight session’s chemotherapy over six months and thirty-two sessions radiotherapy over two months, which had all been completed. At the time of the interview she was on Neophedan (Tamoxifen) for five years and Cipralex 20mg.

The patient had finished her cancer treatment 16 months prior and was in full remission.

### **FIRST CONSULTATION: 30/09/2015**

Because of the distance and convenience for the patient I offered to see her at her home which was quiet and very private and comfortable and suitable for our sessions. We had two sessions of an hour and a half each that were conducted at the patient's home for asking the interview questions. One month elapsed between the first, second and third sessions. The planned questionnaire was followed very strictly.

Before we started with the interview, I again gave her a short, detailed explanation of what this study entailed and what would be expected of her as a participant. I gave her the demographic-, information- and the consent forms to read through in her own time and to discuss it with her family in order to give her more time to decide whether she wanted to participate in the study, and to sign the consent form. I explained the two questionnaires - the HADS Depression and Anxiety Scale and the Female Sexual Functioning Index (FSFI) (see Chapter VI) and asked her to complete it when she had time and give it back the next session. The fact that her participation was voluntary, that she could stop her participation of the study at any time without having to explain herself or stop answering any questions that made her feel uncomfortable was stated again. She said that she understood everything (especially with her medical background) and that she would like to participate in the study and that she had already discussed it with her husband. Both of them felt positive about her participation. I assured her of my commitment to the study and to her as my patient and gave her my cell number and encouraged her to phone me if anything worrying happened in between sessions that she would like to discuss with me. After the formalities and all the explanations, I started with the interview.

#### **Interview.**

**Question 1. How did you feel the moment that you heard that you had breast cancer?**

**Answer:** *I will never forget that precise moment: the exact day, date and place. I experienced total dissociation, dizziness and nausea. It was such a traumatic experience for me and I was totally in shock.*

**Question 2. Did you go to the doctor on your own, or were you accompanied by someone (e.g. husband)?**

**Answer:** *I went alone the first time that I saw the surgeon for the medical consultation and tests, I was also alone when the doctor phoned me with the news that I had breast cancer and that I needed to go in to see him regarding the next step.*

**Question 3. Did you talk about how you felt after the doctor's consultation?**

**Answer:** *The trauma that I experienced was so big; I wanted to be with my family immediately: my husband and my mother. Everybody was shocked and was crying and nobody knew what to say to me.*

**Question 4. What went through your mind after the news that you had breast cancer?**

**Answer:** *The first thing that I thought was that I was going to die: that cancer means "dying". That was my first thought. I have two young children and they were my biggest concern.*

**Question 5. What was the type of surgery that you had and how did you emotionally handle the surgery?**

**Answer:** *I had a lumpectomy and removal of all the axillary lymph nodes.*

I asked about pain in her arm and she said that after the surgery she never had any discomfort, numbness or pain in her shoulder or arm. She said that she felt that she had handled the operation emotionally better than when she had heard she had breast cancer because to her it was something more concrete, something that she understood (the operation itself), and something visible (the wound), something that she could fight against. She felt that, after the surgery, she should have spoken more to her husband and her mother and friends about her feelings.

She realised now that by talking to them and sharing how she felt, she would have dealt better with her emotions.

The patient was on Nuzak 20 mg before the operation.

**Question 6. Did you feel anxious or depressed during your stay in the hospital?**

**Answer:** *Yes, I was very anxious during my stay in the hospital, but not particularly depressed.*

**Question 7. Did you feel the need to talk to a professional (clinical psychologist) during your stay in the hospital before or after the surgery?**

**Answer:** *Looking back now and it is always easier to look back on something and know the right answer: the answer is, yes. If the surgeon had suggested it, even if I had not realised the significance then, I would have benefited from talking to a psychologist about how I felt then, and to put some of my emotions into perspective and also maybe what to expect after the surgery. I realise now, how inexperienced I was as a new cancer patient and how completely clueless I was of what was about to happen.*

**Question 8. Did you understand what was happening with your body and mind (emotions)?**

**Answer:** *No, in spite of my own knowledge of the medical profession, I did not fully understand all the emotions that I was going through or even what lied ahead of me and what my emotions would be during the whole treatment process. The one thing that I did realise was that life must go on, for I have two young children. I just had to go forward.*

**Question 9. Do you think it would have helped if you or your family could have spoken to a psychologist at that stage about your cancer?**

**Answer:** *Yes definitely. I think speaking to a professional person with relevant knowledge about what we were going through would maybe have helped us to be more prepared for the different stages of the treatment and also all the different*

*emotions that we had and not always knew what to do with. Cancer is not something that you can speak about to anybody.*

**Question 10. Was the next step of the treatment chemotherapy and/or radiation therapy well explained to you by the Oncologist?**

*Answer: Yes, I had chemotherapy first. It was first four sessions of the “Red Devil” chemo and then four other chemo’s, I had eight sessions altogether. After that I had thirty-two sessions of radiotherapy. I feel that the oncologist had explained both treatments in a manner that I could understand.*

I asked her if she felt “knowledgeable” about the treatments – she said that the oncologist had explained the treatments to her, but more in a technical manner and more about the physical effects, but nothing about emotions. She said nobody had mentioned or explained the emotional effects and side effects of the treatments.

**Question 11: Did the oncologist at any stage suggest seeing a psychologist or clinical psychologist?**

*Answer: No, the oncologists never suggested that I could see somebody like a psychologist during my treatment. She had only referred me to their social worker, which is as far as I know, mandatory to see as part of their oncology team. I could not understand why I should see a social worker and it was not clearly explained to me. Psychologically I have not benefited anything from our session.*

Our one and a half hour was done and we scheduled another session for the next questions. I made sure that the participant was emotionally okay because it was an emotional session for her having to go through all that emotions. She assured me that she felt fine and that although it was an emotional session, she also felt a bit lighter emotionally.

**Second Consultation: 29/10/2015**

This consultation was in the same place as the previous time (the patient’s home) and we carried on with the interview questions after I had made sure that she was coping well after our previous session and that we could continue with the session. She said that she was still very positive about participating in the study and that



she hoped it would help somebody else who had or was going through breast cancer.

**Question 12. What were your physical side-effects of the chemo-therapy and how did you experience it?**

**Answer:** *In terms of the biological side effects, the worst part for me was the total hair loss, my whole body was hairless, and how that affected my body image which was already compromised by the surgery and the changed shape of my breast. The tiredness was also physically and emotionally very bad for me, especially the severity of the tiredness and the fact that it was so persistent. I had chemotherapy for four months and was tired the whole time. I felt that, in a way, I had to change my “being”, for I am a “doer” and an active person with a challenging job and busy household to a more passive life style during that time. This to me was quite a loss to have scaled down my activities, especially with my children because they are also busy children with busy schedules and I felt not actively involved with them then. I also experienced a lack of short term memory, nausea, aches and pains in my body and a metal taste in my mouth for at least seven days after each chemo. The cortisone that I used caused insomnia and swelling and made me felt very uncomfortable in my own skin.*

**Question 13. How did the chemo therapy affect your family and your marriage?**

**Answer:** *I felt a loss for not being able to do my everyday tasks for my husband and children on the days of my chemo and the days after chemo that I felt sick and tired. I experienced the chemo as a busy and demanding time of traveling and sitting in the chemo room not being able to do anything else. Although I was at home, I felt less available for both my children and husband at that stage of the treatment especially the days that I felt so tired and hopeless, not having enough energy to do anything at all. I thought that the children were ashamed of me (looking ill and swollen with no hair), but realised afterwards that it was my own projection and insecurities about my illness and how I looked at myself. My husband felt hopeless for not being able to help me with my illness and struggle and my son was angry, without knowing why and how to handle it.*

**Question 14. How did the chemo affect your sex life?**

*Answer: We did have sex during that time, but less. To me, everything was about survival. I was in a survival mode, only wanting to get well and healthy again. I did not want to die and leave my family behind. I only concentrated on my treatment and surviving every day. So although sex was not my priority, we still had a good sex life and it did me good when it happened.*

**Question 15. How did the chemo affect your work functioning?**

*Answer: I haven't worked the whole time that I received chemo and radiation therapy. The whole process was to "radical" for me and I was just too tired to work and my focus was not at work at all. Although I was in a position to take off from work, not being able to work was very hard for me and made me feel inadequate and depressed. Work played a big part in my life and identity. The fact that I did not work also made me feel more isolated and I had more time on my hands to have negative and destructive thoughts. Not going in to work every day can make a person feel aimless and out of contact with reality. The positive side about the fact that I could stay home helped me a lot to regain my strength and energy. I didn't have any work related stress which was good for my body and mind.*

**Question 16. Did you feel depressed or anxious or emotionally distressed during your treatment?**

*Answer: Yes, I felt severely down and depressed at that time and scared that I would not be able to go back to normal, or what was normal for me before the cancer. For me the anxiety was worse than the depression. You can feel the anxiousness in your body the whole time; it is like a physical presence, especially the anxious thoughts of the cancer that didn't seem to go away. It was as if the thoughts were just milling around in my head the whole time. I felt at that stage that I was "falling behind" as a person, especially as a mother, wife and career wise because of the cancer. Cancer treatment was actually taking you away from your "normal" life and "normal" activities and I was very concerned about the time away from my home and family, especially with the children.*

**Question 17. Did you speak to anybody about these feelings?**

**Answer:** *Yes I did. I spoke to my mother, my husband and to my close friends. I have an extremely good and close support system which supported me very well at that time as well as now. The support that I got was the one thing that kept me going.*

**Question 18. Do you think it would have helped to have spoken to a psychologist during the time of treatment?**

**Answer:** *Again, looking back now, I would have liked to have seen a psychologist before and after the treatment, but are not sure how it would have fit in during the treatment. Because it was not suggested at any given time during the treatment, I never actually thought about it. It was mandatory to speak with the oncology department's social worker, but I would have preferred a psychologist. I think I would have been more prepared and equipped for the whole process of treatment if I saw a psychologist from time to time. Even just to have known that there was such a person to go to if needed. Because it is such a new and completely unfamiliar situation, you need to learn new skills from somebody who has the necessary knowledge and know-how of how to handle yourself, your family and the situation.*

**Question 19. What were the side-effects of radiation therapy?**

**Answer:** *Fatigue again, pain and sensitivity in the breast area where they applied the radiation therapy.*

**Question 20. How did you cope with the radiation therapy?**

**Answer:** *Although I had side-effects, to me radiation was much easier both in a biological and emotional way than the chemo. It was however a practical inconvenience because we had to travel quite far every day for just a couple of minutes.*

**Question 21. Were there any emotional effects of the radiation therapy?**

**Answer:** *I didn't find it emotional as the case was with the chemotherapy.*

**Question 22. Where in the trajectory of the illness and treatment did you feel the most emotional?**

**Answer:** *My most emotional time was when I was diagnosed with breast cancer, at the very beginning. It was such a shock and the experience was very traumatic for me. I was, before and after the breast surgery and before my first chemo, very emotional and scared not knowing what to expect at all. After the end of the treatment, when I thought I would be glad and happy, the anxiety was bad again. The shift from being an active cancer patient, with all the medical support and constant contact with the oncology staff, to just being a “normal” person again without that support, made me feel vulnerable and unsure of myself. Because I was so anxious and depressed, I have decided to go to a psychologist for therapy.*

**Question 23. Did you feel comfortable speaking with your oncologist about your emotions and sexual fears? Would you have felt comfortable?**

**Answer:** *No, not about my personal feelings and sexuality. I felt our relationship, although very good, was not on a personal level. It was more on a very professional level, more medical and biological than emotional.*

**Question 24. Did you suffer from depression and/or anxiety before the diagnosis of breast cancer? And did you receive treatment for it?**

**Answer:** *Yes I was diagnosed with depression and was also treated for the condition earlier in my life, both with psychotherapy and an anti-depressant.*

**Question 25. Would you say that you developed depression and/or anxiety after the diagnosis and treatment of your cancer?**

**Answer:** *Yes I have developed both, especially anxiety, but the oncology team did not discuss the conditions with me. Although I am in the medical field, I didn't realise that I was busy developing these conditions. I was not given the option of treatment by the team. I realised on my own that I was depressed and stressed and made my own appointment, after my cancer treatment was finished, with a psychologist.*

**Question 26. Do you experience any sexual problems because of the cancer or the cancer treatment? Did you have sexual problems before the cancer?**

**Answer:** *We never had any sexual problems before the cancer, but after the treatment I experienced severe problems in that area and saw it as a huge loss.*

*Because of the type of treatment, (Tamoxifen), I had a complete lack of oestrogen (which happened rather suddenly) and I had to drink an oestrogen suppressor for the following 5 years. This took me completely by surprise. I was not prepared for the suddenness of the menopause. Although I was told about the treatments, the chemotherapy and the radiation and their side-effects, it was never explained to me in detail what I could expect of my body and emotions, or what I could do to adapt to the situation. Nor was I referred to a psychologist to attend to the problem. It was just not a subject of discussion. Nobody had spoken openly to me about my sexuality and sexual functioning. I had to struggle through that on my own, not having the confidence to ask about it.*

**Question 27. How did the cancer and cancer treatment affect your self-image and self-esteem?**

*Answer: It affected me very seriously. In terms of my self-image; I don't look the way I had before the cancer. The form of my body and weight has changed drastically. The way my body used to react sexually has also changed, it is not possible for me to reach an orgasm anymore, and it is as if my body doesn't want to react in a sexual manner because of the cancer and treatment. I don't understand my body anymore, especially not in terms of my sexuality. To me it was another thing to worry about with all the other worries regarding the cancer and my depression and anxiety.*

**Question 28. Do you think it is necessary for a psychologist to explain the influence of the cancer treatment on your sexuality and the changes it can create to you and your partner?**

*Answer: Yes! Yes!*

**Question 30. How do you handle the cancer as a chronic illness?**

*Answer: I haven't handled it very effectively up till now, especially the effects that the hormones have on me. It affects me emotionally and sexuality the whole time. I have never thought about cancer or my cancer as a chronic disease. I only now start to understand the treatment's side effects better (after the treatment), living with it on a daily basis. I think that having understood it better and in a more knowledgeable framework, I could have coped better with the whole journey.*

In both the interview sessions with the patient there was already a therapeutic process which had begun with the emotional catharsis in answering the questions and remembering the emotions. The patient had a very prominent need to talk about her experience and emotions regarding the cancer and cancer treatment and how her family experienced her cancer. She also felt that she never had had the opportunity to be seen by a psychologist and felt that it could have saved her a lot of agony if she could have learnt about the process and had had the opportunity to vent her emotions.

She said that even just talking to somebody with knowledge about the psychological side of breast cancer, already made her feel better and more “normal”. She was looking forward to having therapeutic sessions with me regarding her issues around her breast cancer and how she was functioning. We ended the session after one and a half hours and rescheduled for very early in the next year after the holidays.

### **Third Session: 29/01/2016**

The patient was ready and eager for a therapeutic session after the previous two interview sessions. The venue was the same as the previous two times.

The patient told me that she had had another cancer scare the previous month, with a lump in the other breast. She had to go through the whole process of a mammogram, blood work and biopsy. She had experienced this in a very negative way, opening all the “old wounds”. The waiting in between the procedures and the results caused hard core anxiety. I gave her time to talk about her emotions and how it made her feel. We used it as an emotional expression or catharsis.

She said that the incident made her unsure of the surgeon’s decision not to do a mastectomy. (The patient had previously had a lumpectomy). She felt that she was not really part of the decision making process after being diagnosed with breast cancer. She said she was too shocked and traumatised after the diagnosis and that everything happened so quickly that she felt that she wasn’t “present” at that time and that everything just happened “around” her.

I used her anxiety over this incident (with the second lump) as a platform for the therapeutic session. I explained the pathogenesis of anxiety and depression (for

the sake of information and knowledge) in the context of cancer and that cancer-related anxiety was not an unrealistic anxiety or fear. The aim was to normalize her fears and anxiety. She said her biggest fear (throughout the cancer treatment and up till the present) was the fear of death: not so much for herself, but for her children, who were still young. Giving the patient the opportunity to talk about death and the fear of dying had a positive impact on her. She was relieved to speak about it without feeling guilty or “ungrateful”. She said that her fear and anxiety was worse after the end of the treatment when everything was supposed to be “back to normal.” The biggest disappointment to her was the realisation that the anxiety and fearful thoughts would never end, that there would never be a “full stop after the sentence”.

At that stage she presented with a General Anxiety Disorder (DSM 5), which had been diagnosed by a psychiatrist and she was prescribed Cipralex 20 mg. It reduced the anxiety symptoms. She had never, before the breast cancer diagnosis, been diagnosed or treated for Anxiety Disorder, but had been diagnosed with a major depression previously before the breast cancer.

I reinforced her knowledge about how the mind worked regarding stress and trauma and the chemical impact it could have on the brain and body. We also talked about the discomfort it can cause when left unattended (e.g. developing depression, anxiety or even post-traumatic stress disorder). We discussed the importance of allowing herself to feel anxious without feeling guilty. To be aware of the fact that she could take control of her (anxious) thoughts by being consciously aware of the thought(s) and to replace them with more positive and realistic thoughts or focusing away from thoughts that disturbed and disrupted her mind-set and mood.

She said that when she felt anxious, it helped to get up and walk around and find an activity to distract herself from her negative and anxious thoughts. I reinforced this behaviour, because diverting thoughts and behaviour also meant focusing away from anxious thoughts and taking control over your mind reminding yourself that you are not dying.

Another skill that we worked on was relaxation, especially breathing. Breathing is not only a biological method to reduce anxiousness, but also (again) a way to

focus away from stressful thoughts and consecrate on something else. When the body is relaxed and the breathing is steady the mind is clearer to think rational thoughts. It made a lot of sense to the patient and she fully understood how these skills could help her with her anxiety. In my experience, even people with the appropriate knowledge about psychology and how the body works, still need to hear this in a professional setting to internalise the knowledge and use it accordingly.

The session lasted one hour and we ended it by making another appointment for one month from that date. I made sure that she was comfortable with ending the session.

#### **FOURTH SESSION: 29/02/2016**

This session consisted of sex therapy in an individual session.

We decided that we were going to talk about sex in the session because of all her questions about her menopause and her lack of libido. The patient began by saying she was completely surprised and overwhelmed by the unexpected sexual changes during and after the cancer treatment. She said that although it was mentioned briefly by the oncologist, especially the menopause, it was never discussed in depth or explained in terms of symptoms or the influence on the quality of her sex life and life in general. Because of the lack of communication between her and her oncologist in this field, she didn't feel comfortable to discuss her sexual status and accompanying emotional status quo.

We discussed the changes in her body image because of the cancer and treatment, she said she looked and felt completely different after her treatment and that she had to get used to an "older" body. We talked about how to accommodate the changes in her body and breast (the scars) and how to make peace with it on a conscious level. We talked about the complete lack of oestrogen and androgen because of her menopausal status and how it affected her libido or sexual desire. We also discussed what she could expect of her sexuality in the future. She said the changes in her sexual functioning and lack of oestrogen was one of her biggest losses throughout her breast cancer and made a huge impression on her emotional wellbeing. I explained the grieving process to her,



although she was familiar with it, and said that she should allow herself to go through this process first and make peace with this loss. Although she was in remission, she had never given herself the time for grieving her losses. She understood that, only after working through the emotions, you could get to the acceptance phase and make peace with a different mind and body regarding your sexuality. We also touched on self-esteem and self-confidence and embraced a new “post cancer” identity in a very conscious and cognitive way. We discussed the abruptness of the onset of her menopause and the severe symptoms which she was not prepared for. This gave her the power to control, understand and implement it in her “new” life: especially the chronicity of the sexual changes. Another loss was that of intimacy between her and her husband. Because she did not have the knowledge or confidence to have spoken about her lack of sexual interest, sexual functioning and changes in her body, they did not communicate the problem properly. This lack of communication between her and her husband then led to an absence of their sexual functioning and intimacy. I explained to her that I often find this in working with cancer patients that because they cannot have sexual intercourse, they abstain from any form of sexual expression, feeling scared that any form of touching might lead to sex or “misleading” the partner that they wanted sex when they were not in the biological or even psychological position to do so. By not talking about their feelings, they rather ignored any form of intimacy. It is important for her to realise that other patients in her position experience more or less the same sexual uncertainties and functioning as she did. One of the therapeutic goals here was to go back to basic sexual behaviour, (touching and caressing) and learning to look at, and experience you and your partner’s bodies from a new angle. We later discussed it again with the husband in a couple’s therapeutic session. I found that it was often difficult for patients who had had a period of sexual abstinence to just start with the sexual act immediately. Therefore “going back to basics” first, is important to regain some of the trust and comfort with each other’s bodies. I explained to the patient the “practicalities” of sexual functioning in menopause, for example, the using of lubrication (different types), implementing new strategies e.g. massaging, and different positions and experimenting with new techniques to reach orgasm. This was also a good time to invest in a new book (or two) reading and learning new sexual behaviour (and skills). The more the couple talked about sex, the more comfortable they would get

in performing the act. Sex also has to do with a mind-set and because of the lack of androgen and oestrogen, there was an accompanied lack of desire (libido) and sex became more a process of thought than biology. I explained to her that it was important for her and her husband to understand the lack of sex drive in a biological sense, otherwise they might feel that their sexual partner was not attractive to them anymore, hence the lack of sexual enthusiasm and the likelihood of it affecting their sexual confidence. The lack of sexual drive had nothing to do with them as persons, but was biological.

By giving the patient the opportunity and safe environment to speak about sex, her sexuality and sexual functionality, she felt much more liberated about this “forbidden” subject. By understanding and normalizing her fears, questions and “issues” about her sexuality and her “different sexual image”, she understood it better and felt more in control in this area of her life.

At the end of this session, the patient said she really felt that she understood her own body better, as well as the permanent impact of the breast cancer on her sexuality. Because of the new skills and knowledge, she felt more relaxed about sex and intimacy. Instead of just another loss and stressor in this jungle of effects and side-effects of breast cancer, it was something that could be treated and resolved. The session lasted an hour and 15 minutes. I made sure that she was comfortable to end the session and we schedule another session with her and her husband.

#### **FIFTH SESSION 29/03/2016.**

This session consisted of sex therapy with the couple.

I explained to the couple what sex therapy entails and what they could expect of the session. Both felt that the session was necessary for them and they felt ready for the session. The patient’s husband was very positive about the session and participated in a constructive manner. The patient’s husband agreed with his wife that they did not have proper information about the changes in their sexual functioning before, during or after the treatment. I explained to them the importance of understanding that the husband of the breast cancer patient still has his “normal” libido and sexual needs and that just ignoring them because of his

partner's illness is counterproductive for the couple. Therefore it needed to be addressed.

The main aim of this therapeutic session was, (1) to enhance communication between the couple about sex and emotions revolving around sexual functioning and, (2) to provide knowledge about the influence of cancer and cancer treatment on menopause and sexuality. We agreed to the fact that if a couple was not used to talking freely about sex or if communication regarding sex became difficult because of an illness, it was easier if they could speak through a professional person (as in this case, a psychologist). I took the lead in asking questions regarding their sex life and gave them examples of specific, general scenarios from literature and other couples concerning sexual problems relating to this given scenario. Examples of this are that breast cancer patients often complain about their lack of sexual needs and that they don't feel up to any sexual activity. Their sexual activities decrease from a couple of times a week to nothing or very little. Even if they do have sex, the women complain about their incapability to reach an orgasm. Both the patient and her husband could relate to these examples given. During the session the couple started speaking freely and comfortably about their emotions and their various thoughts about sex and sexuality throughout the whole cancer experience. Both disclosed that they did not know how to handle their sexual functioning because of their own anxieties around their feelings about sex and the cancer. The one thing they did not understand was the patient's lack of libido, or any form of sexual contact, or conversation, because before the cancer they had had a good and satisfactory sex life. I explained that it could have happened because cancer is such a traumatic disease which affects all forms of functioning, sex life included. I explained to them what a chemical induced menopause means and the immediate effect on the body and mind. This knowledge set the husband at ease, understanding that the lack of sexual activity had nothing to do with him or their sexuality, or even how she felt about him, but was a mere side effect of the cancer treatment and something that could be worked on. I suggested that a good place to start would be to read some literature about sex and to talk more about how they could enhance their sex life by engaging in sexual communication and even trying new positions or new places where they could have sexual interactions. I explained that if she found it difficult

to reach an orgasm, they could experiment with new ways to improve sexual satisfaction and the importance of using vaginal moisturisers and lubrications.

He understood the chronicity of this and that they both had to work hard to create a new and exciting dispensation that would work for both of them. I explained to the husband the importance of acknowledging his own losses regarding their changed and challenging sexual functioning as well as his wife's losses and changes especially to her self-image. They should work through that before they could actually build a new and fulfilling sex life together. By understanding their "new" sexuality, they could use it to grow individually and as a couple. Both the husband and wife had exceptionally good insight in this therapeutic process and felt very positive and motivated about implementing the new skills.

The next session would be about feedback from this session and would be the last session. The patient also felt ready to end the therapeutic process, for she was feeling more knowledgeable and strong in terms of living her life in the aftermath of cancer.

#### **SIXTH (AND FINAL) SESSION: 11/06/2016**

This was the final session that was scheduled to obtain feedback from the previous sessions and also to conclude our therapeutic process. I asked the patient how she felt, now, after our sessions and she said she felt that her "rhythm" was more or less back to where it was before the cancer. She said being back at work and being able to participate in all her "normal" daily activities made her feel more like herself again. She said she realised that for the rest of her life she will be confronted with the "aftermath" of cancer and that although her cancer was in remission the "cancer file" in her brain will never be deleted. She said that, through therapy, she accepted the fact that the cancer did not only bring permanent biological changes, but also permanent psychological changes. She also understood that you could learn to adapt to both, through conscious efforts to grieve your losses, and learning new coping mechanisms for a new and "unwanted" chronic situation. She said she had learned the importance of working through her trauma step by step by talking about it and working through all the emotions before making peace with it and accepting it: to learn to "live" with the aftermath of cancer instead of "fighting" it. She said that the receiving of relevant

information and knowledge regarding the effects of cancer and the treatment, especially on her emotions and sexual functioning, was one of the things that she valued most during the therapeutic process. She said that it opened a lot of doors for her in terms of understanding what she was experiencing and why. She said that one of the most difficult issues for her during the whole experience of cancer was the fact that she could not understand the reason or purpose of the cancer and why it had happened to her and what she would do with the devastating impact of it for the rest of her life. She said that it was quite a challenge to be able to come to terms with the reality that there was no answer or explanation for this and that she had to accept and make peace with the breast cancer and live with it even though she didn't understand it. She said she learned to look at her life goals from different angles and had to redefine and adjust some of it, especially regarding her work. She changed her whole working structure to allow more time for activities that were more relaxing and beneficial for her health and relaxation. She said she was also more mindful of situations that create stress and affects her mind and body and to either avoid it or handle it effectively. She said she realised that the cancer had affected her whole family and that they would have to keep on working together to accommodate the long term effects of her cancer. She said as a family they were very supportive of each other and engaged in a lot of activities together. She further stated that her husband was very supportive of her during the entire time of the treatment and they were both very focused on the practical workings of the household to ensure that the effect on the children were minimal. She said he was often the "voice of reason" when she was irrational or felt incapacitated because of her tiredness or stress he made her feel safe and she felt very thankful for his good support. She said that both of them benefitted a lot from the sessions regarding their sexual functioning since both of them were clueless as to what was happening to them sexually. She said that understanding the biological and psychological side-effects of menopause on her sexuality and especially her lack of libido had clarified a lot of her behaviour for both her and her husband. She said they could look at their sexual difficulties through the framework of the cancer treatment instead of taking it personally and that it made sense to develop a new outlook on, not only sex, but also intimacy and to learn new skills regarding their sexual functioning.

She said because of her occupation she was able to diagnose her depression and anxiety early and that being on an anti-depressant was a huge help in adapting to the cancer process and stabilising her mood. She said if she could describe the therapeutic process for herself: *“it was a life-line to grab onto when I was drowning in a sea of emotions, which dragged me back to the surface again”*. She said that the understanding of the reality of what the cancer was doing to her, and being able to put her own feelings and experiences in context was what brought her back to the “surface”.

We ended our session and whole therapeutic process on a positive note with the understanding that she could contact me again if she would like to continue with the therapeutic process.

## **PATIENT II**

Patient II was recruited from a state hospital. After obtaining ethical clearance (see Chapter VI) I was granted permission to attend a meeting with a group of newly diagnosed breast cancer patients at the hospital. This meeting was held in the oncology ward where all the newly diagnosed breast cancer patients met at a scheduled date and time to receive information about certain particulars regarding their chemotherapy appointment dates and to be familiarised with the place, procedures and the oncology personnel for the period of their treatment. During this group meeting an oncologist explained to the patients what chemotherapy entails and what to expect in terms of general side-effects as well as the way forward after they complete the treatment. At the end of the group session, he introduced me to the group and the personnel and briefly explained the reason for, and aim of my study. After the informal information session was over, I interacted with group members individually, recruiting volunteers for my study. I selected patients falling within the age interval of my planned sample which was 30 to 65 years. I again explained to each person in a private conversation what my study involved. Initially three patients were recruited but one dropped out of the study after the first consultation with me.

I took each patient’s contact number and made our first appointment which would coincide with their following chemotherapy appointment at the hospital. I phoned

each patient the day before the scheduled date to confirm our appointment. The demographic information of patient 1 is presented below.

**DEMOGRAPHIC INFORMATION:**

**Age:** 52 years

**Marital status:** married

**Children:** two adult children

**Highest education level:** matric and tertiary diploma in Management

**Occupation:** housewife

**Diagnosis:** Stage IIB Breast Cancer

**Date of diagnosis:** November 2015

**Surgery:** lumpectomy of the right breast and lymph nodes under right arm. (7 December 2015)

**Breast reconstruction:** no breast reconstruction

**Treatment:**

*Radiation:* none

*Chemotherapy:* busy with the treatment. Had two of the six chemo sessions. Four sessions left – the date of the last chemo was 09/06/2016.

*Hormonal therapy:* none

*Anti-depressants:* none

*Pain medication:* none

*Psychiatric treatment history:* she had never before been treated for a psychiatric illness

**Diagnosis**



The following information I obtained from the patient herself.

The patient had been diagnosed with breast cancer on 10/11/2015 after she had felt a lump in her breast four months previously. She had a mammogram and a fine needle biopsy on 17/11/2015. Following this she had a lumpectomy (right breast) on 07/12/2015. They removed an 18 mm tumour and some axillary nodes. Subsequently two nodes tested positive for cancer.

The diagnosis that was obtained from her medical file was as follows: Stage IIB Breast Cancer of the right breast – pT1c N1 M0.

### **Treatment plan**

Chemotherapy: she was scheduled for six chemo therapy sessions every three weeks. After finishing the chemotherapy she would be re-evaluated for surgery if necessary, with a scheduled date for surgery on 11/07/2016 and the possibility of radio-therapy.

### **FIRST CONSULTATION: 14/03/2016.**

I met the patient formally for the first time on 4/03/2016 for a therapeutic session. I saw the patient at the hospital, as agreed, for an hour session in one of the hospital's consultation rooms in the oncology department. We used one of the oncology ward's consultation rooms, which was small and impersonal, but quiet, private and adequate for our needs. We had scheduled all our appointments on the same days as her chemotherapy appointments for practical reasons. These included her presence at the hospital and the cost effectiveness for her in terms of traveling to the hospital.

Before we started with the session, I gave her a short but detailed explanation of my study for the second time regarding what the study entailed and what would be expected of her as a participant. I avoided complex medical terminology. I told her that one of the aims of the study was for the oncology team, including the psychologist, to better understand the psychological needs of the breast cancer patient in order to provide a holistic service that would enhance the quality of life of all breast cancer patients and their families. Learning by way of her experiences,



as related to me, the medical team could support other breast cancer patients in the future.

I emphasised the fact that she could stop her participation at any given time without giving a reason. She could leave the interview at any time or refrain from answering any questions that made her feel uncomfortable. I gave her the demographic form, the information form and the consent form to read through at home on her own time and discuss it with her family and husband which would give her more time to decide whether she wanted to participate in the study. I asked her to explain the study to her husband and to ask him if he was comfortable with her participating in this study and if he would later attend a session with her. She could sign the consent form and return it at the following session. I also gave her the two questionnaires to complete at home explaining them to her. The questionnaires were the HADS Depression and Anxiety Scale and the Female Sexual Functioning Index (FSFI) (see Chapter VI). I assured her of my commitment to the study and to her as my patient and gave her my cell number, encouraging her to phone me if anything troubled her in between sessions so that we could discuss the matter.

She had already received her first chemotherapy three weeks previously and was scheduled for her second session of chemo therapy (“Red Devil”) after our session. She referred to the chemo therapy as the “Red Devil” because that is how the oncology sister had explained it to her. I told her that the term was the “nickname” for a type of chemotherapy which contains beetroot extract as an ingredient and made it red in colour (Kapadia, et al., 2011; Opperman, 2015). She told me that she was already experiencing some of the side-effects that the oncologist had informed the group about. These were immediate hair loss, mouth sores and changes to her finger and toenails.

After the formalities and the explanations I gave the patient the opportunity to talk. Without any prompting she began to talk about her experience of breast cancer from the very beginning. The patient had found a lump in her breast and had had tests confirming the cancer. By the time she had seen the oncologist she was extremely anxious and stressed and the oncologist immediately referred her to a social worker which is part of their oncology practise. She said she could not say

whether the session had helped her in any way in terms of her emotional well-being. The interview had been done more in a “technical manner” relating to her what she could expect from the treatment in a practical way. She only saw the social worker once and was thankful for the practical information but still felt extremely anxious and did not know how to handle her feelings. She said that she was not an anxious type of person and therefore did not have the know-how to deal with extreme stress such as her cancer. She had started off as a private patient, but because of the costs, she was receiving her cancer treatment as a state patient.

The patient said that her family and their closeness and constant support had helped her to cope up to that point. Her husband of nearly thirty years and adult children were very supportive and spoke openly about her cancer. She had immediately bought a book about cancer which helped her with certain questions but said that “over information” made her more anxious and she preferred to know only the basic information. She did not want to know about the “time frame” connected to her cancer. She said that what she wanted and needed is someone to talk to about the treatment and emotions and what she could expect, rather than more cancer statistics. She said because of this she had immediately decided to participate in this study when I had explained the specifics of the study and the therapeutic interventions on the very first day at the group discussion.

She again said her hair had started to fall out immediately after the first chemo session, but she felt she was ok with it because it had been explained to her and she had been prepared for it to happen. Again the way her family and especially her husband had supported her made her feel safe and that she was still wanted as a wife and mother. She said spontaneously, that her husband had ensured her that she was still attractive to him and regarding sexuality, he still felt the same about her as before the surgery. She began to talk about sex spontaneously although I had not asked her any questions or prompted her regarding their sex life. They still had a “normal” sex life and she found it very reassuring and it had had a calming effect on her. She and her husband had always had a good and open form of communication, which give her the freedom to talk openly to him about her feelings and fears.

I asked her to tell me about her experience of the first chemo therapy. She said she could feel after the chemo that her energy levels were lower than usual, but found she had more energy in the mornings and she had chosen to do all her house work, social meetings and other activities at that time. She stayed busy with cooking, cleaning and gardening. Her energy levels decreased in the afternoons, and she then rested and became more passive. She felt that the cancer was more of a challenge for her thought processes than anything else and she was very focused on turning her thoughts from negative to positive. She always had had a good way of coping with stress and never let negativity overrule her thoughts and wanted to start with mild exercising. We discussed the benefits of exercising and the positive effect it could have on her body and mind, but I advised that she discuss it with her oncologist firstly.

The side-effects that she had experienced after her first chemo had been nausea from day three although she had been given medication for it. She had also experienced tiredness more or less three days after the chemo and again repeated that her hair had fallen out immediately.

We ended the session after an hour and booked our next appointment which would be three weeks from now and just before her third chemo session.

#### **SECOND CONSULTATION: 04/04/2016.**

This consultation took place in the same consultation room as the previous session and the order of events were the same. The patient went to draw blood first; we then had our therapeutic session for an hour and afterwards she went to the chemotherapy room down the corridor from where we were. This was the third "Red Devil" chemo and the last one before she would begin a new chemotherapy.

The patient looked less stressed than at our first session and her opening words were: *"I couldn't wait for this session."* She began talking immediately about how she felt and especially how she had felt after the previous chemotherapy and consultation. She had just found out the date of her next surgery from her oncologist. It would be on 11 July 2016.

Without me asking any questions she talked about the side-effects of the second chemotherapy which had started on the third day after it:

- She had developed a bad cough and tight chest
- Her nails had turned blue
- She had become very tired and continued to be very tired. It was much worse than with the previous session. She also said that the tiredness was more severe and was lasting longer.

I asked about nausea and vomiting and she said that she had not been nauseas at all and that they had given her medication to prevent it. The tiredness was affecting her emotional health and psyche the most, because it was changing her specific level of functioning that she was used to. She had been a very active person who liked working in and around the house, especially gardening. These activities were what defined her as a person and made her feel useful. She said that she constantly felt, without any reason that she should prove to her husband and family that she could still do everything in and around the house in spite of the cancer and the treatment.

### **THERAPEUTIC INPUT**

I explained the dynamics of chemo related tiredness to her – telling her it was different from other forms of tiredness regarding its severity and persistence. It was a very common side-effect of chemo therapy and that it could be quite a prominent and distressing experience. Chemo-related fatigue not only makes physical action difficult, but can also cause a lack of interest and an impairment of the short-term memory, attention and concentration. It was important for her to understand her own unique pattern of tiredness, identifying the specific day after a chemo session when she felt most tired and the specific time of day she would feel the worst. I tried to put her tiredness within the context of her treatment and to normalize her feelings about it. We also talked about accepting the tiredness as a passing or interim element in her life as it was part of her treatment. She could time-manage her day around her fatigue and involve her family into her “fatigue time-schedule”. We looked at specific practical things that she could do, e.g. resting on the bed with a book or watching TV, without feeling guilty or thinking that she was “lazy” which would be a way of dealing effectively with her situation. She said that she could take up knitting again for this was something “passive”

and she was actually looking forward to it. Another practical plan she thought about was for them to hire help once a week to relief her from some of the household chores. She said this made a lot of sense to her but she had not thought about it before and that she would discuss it with her husband. I told her that because her situation was different from before she was diagnosed with breast cancer; she would need to think about alternatives to help her cope.

I helped the patient understand the tiredness, putting it within a rational framework assisting her to work around it instead of becoming stuck with it. This made her more relaxed about her fatigue, realising that there was nothing “the matter with her”.

We also talked about her irrational thoughts that she had to “prove herself” to her husband and grown-up children after all these years. Did they really expect her to prove herself to them? And her answer was “no, never”. The family all had very good and solid relationships with one another and good communication. She could learn to identify irrational thoughts which were not true or based on facts. She could change them to more rational thoughts, e.g. “I do not need to prove myself to my family after 30 years and they accept me for who I am, even now with the cancer”; “they still love me and I still love them”.

I asked how she felt about the scheduled surgery and she answered that she did not know what they would do, for they had not decided yet. Everything depended on the outcome of the results after the chemotherapy. She still did not know what stage of cancer she was in and she wanted to know. She felt that there were not good communication between her and her doctor and because of that she did not have the confidence to talk to him about anything or ask him any questions. She felt that he was in a hurry when she was in consultation and did not interact well with her. She experienced this as a problem, because it made her anxious and not able to talk to the doctor.

She spontaneously began to talk again about her emotions over the previous two weeks because of the tiredness and the feelings of depression (that was her own words). She said that she had been extremely moody and “down” during the previous two weeks. She said she had made a point of trying to explain how she felt to her family. She could relate her mood to the effect of the chemotherapy

because she was usually not a depressed type of person. She talked about her hair that fell out and I asked her how she felt about that. She said because her husband was so positive and nice about it, she felt that she could live with it for the time being. She had bought herself a wig and some headbands, but her husband encouraged her to walk around at home without her wig or something on her head. She said because of that she felt her self-image was still good and that she was not ashamed of her hair that had fallen out. She then talked again about the good support from her husband and children.

Before we ended the session she again emphasized how much she looked forward to our sessions although she had good communication with and support from her family. She felt she needed to talk to a professional person with knowledge about the process and how she felt about everything. We ended the session which had lasted an hour by making a new appointment dating it within three weeks' time, coinciding with her next chemo session.

### **THIRD CONSULTATION: 28/04/2016**

The patient began the session by talking about the previous chemotherapy treatment, saying that she was very tired and that the side-effects were getting worse. She said that day she was starting with the new chemotherapy named Taxol. She was to have three of these treatments and hoped the next three chemo sessions would be better than the "Red Devil". She said (without me asking) that the worst side-effect of the chemo was the persistent tiredness, especially from the second day and what really helped her to get through it was the support of her whole family. They made sure that she was ok and that she eat properly every day. She said she did not know what she would have done without them.

I asked her about her emotions: she said that she still felt fine and in control of her emotions and life and that the mere fact that we spoke every three weeks gave her the courage to carry on, knowing that she could vent her feelings to somebody that understood the process of chemotherapy and was outside of her family. She said that speaking about the cancer and treatment and getting information about it, made it less unfamiliar and scary and worrying.

I asked her about menopause: she said that she had not been menopausal before the beginning of the treatment but that up, until then, nobody had spoken to her about menopause or menopausal symptoms because of the treatment and that she was not sure what to expect. She said that if this was the case, she would like to know more about treatment-related menopause. Although she was still pre-menopausal, she realised that she was at the age where the symptoms of menopause might start and she did not feel negative about “normal” menopause.

### **THERAPEUTIC INPUT**

Because the patient felt so tired and negative about her treatment I made a decision to talk about accommodating and controlling her negative thoughts regarding the treatment in order for her to feel more in control of the cancer situation, but to first answer her questions about menopause.

I explained to her that menopause can be a side-effect of chemotherapy, which is called a chemically induced menopause. Menopause means that the body produces less oestrogen which causes menstruation to stop as well as other symptoms. These symptoms include hot flushes, heart palpitations, an inability to concentrate and impaired short term memory, weight gain, mood swings, a probable decrease in sexual desire and vaginal dryness. I explained that vaginal dryness could cause pain and discomfort during intercourse and it was important to use enough lubrication and have a longer foreplay before actually engaging in sex. If necessary, they could change their sexual patterns to adapt to the “newer” status quo. We decided to talk about sexuality at a later stage when the patient thought it necessary for their sexual functioning was still good and satisfying. At that point she preferred to talk about her negative feelings regarding the chemotherapy.

We agreed that cancer is a traumatic illness and that the cancer treatment which, in her case, was the chemotherapy, is stressful and unfamiliar and that negative thoughts and worries should be seen as normal in this situation. She should learn to allow and acknowledge negative thoughts, speak about them and their accompanying emotions and put them into perspective of her illness. She could consciously focus away from negative thoughts and force herself to think about things that would make her feel better.

She could learn to see the side-effects of the chemotherapy from a different angle, realising, for instance that they were not side-effects of the cancer, but of the cancer treatment. In this manner they could count as “good” side-effects because they would most probably make her healthy or better again.

We spoke about her tiredness extensively, for this was her biggest concern and caused much anxiety. We again discussed how to plan her day around the tiredness in order for her to rest enough without feeling guilty (she still sometimes felt guilty for not doing as much as before the chemo treatment). She gave feedback concerning our previous session where she had agreed to consider help with the housework and that she and her husband had hired a woman to help her with the house chores. She felt very positive about this step and revealed that it was actually not as difficult as she had expected it to be. I explained that resting enough and conserving her energy meant she could use it for more important activities such as looking after herself, doing relaxing activities and spending quality time with her husband and children. She could still do some of the housework, but at a different pace as before the cancer. She explained the importance of doing her “duty” in their household in order for her to feel “normal” and womanly and not “sickly”. I gave her the reassurance that it was good to still want to continue life in a “normal” fashion. She could do that to a certain degree but had to develop new ways of doing everyday chores so as to manage her time well. She should time-manage her day and not make her self-worth dependent on the amount of chores she was able to do. We talked about prioritizing her activities. She should decide which activities were the most important in terms of quality of her life and do those first when her energy levels were higher and leave the rest either for somebody else to do or for when she felt less tired.

The patient said that this made perfect sense to her and that she felt more positive than before the session. She said that every time she walked out of a session, she felt more at ease and knowledgeable about what was happening to her and what she could do to make things better for her. We ended the session on a good note and made the follow-up appointment for three weeks from then to coincide with her next chemo session.



#### **FOURTH CONSULTATION: 16/05/2016**

The patient looked tired and emotional. We started the session with her agonising over the new chemo that she had started the previous time. She said it was the most terrible experience up to date and that she felt that nobody had prepared her for the “shock” of this new chemo and its side-effects. Because it was so unexpected, the physical and emotional consequences were very traumatic for her and although she was not an anxious type of person, she was very anxious and tense because of “not knowing” what was happening to her. She thought that she would feel the same or even better than with the “Red Devil” treatment. She looked angry and said that she felt angry for not been given the chance to prepare herself for the new chemo because of the lack of communication between her and the oncologist.

The side-effects as she explained it to me:

- Her whole body was sore, very much so. She could not sleep because of the extreme pain. During the little time she could sleep, she had nightmares because of the pain. She said that she had once even vomited because of the pain – and she had never vomited as a side-effect of the chemo. This was very bad and scary for her.
- The tips of her fingers were “dead”. Her nails had also turned blue. Her leg from her knees downward felt “weird”. Especially the soles of her feet felt “weird” and very sensitive as well. The soles of her feet were swollen in such a manner that it was uncomfortable for her to wear shoes or to walk. Because she had not expected any of these side-effects, it was a shock and she was very, very anxious and scared not knowing what was happening to her body. She said she thought because she is a diabetic her hands and feet were worse, but she was not sure.

She said she had seen her doctor just before our session and that he had prescribed Vitamin B and mentioned that her sugar count is too high, but that they would attend to it. The doctor also confirmed the date for her next surgery (11/07/2016). She said that although she would have liked to, she had not spoken frankly with the doctor about her feelings and even about her physical reactions

regarding the chemotherapy and her lack of knowledge about the side-effects. I again encouraged her to speak to her doctor regarding the cancer and chemotherapy and ask him questions about matters that were unclear to her. She said that she was disappointed in the hospital personnel and the doctor for not informing her about the severe side-effects of the new chemotherapy and what to expect from that. She felt that if the oncology personnel had not looked out for her as a person because they withheld information from her. She saw this as a setback for her in terms of her emotions and adaptation to the treatment.

She said that for the first time – after hearing when the operation would be – she was scared. She said up till then, it was something that had been too far in the future. She said that she had been in denial and also too busy with the chemotherapy and that she had not thought about the operation at all. After hearing the confirmation of the date, it became a reality for her and she felt nervous and scared.

### **THERAPEUTIC INPUT**

Because the patient was so emotional and unsettled, I let her talk freely about how she felt (as an emotional catharsis) and tried to normalize her emotions and fears by saying that pain can be a prominent side-effect of chemotherapy and often co-occurs with cancer-related fatigue. Pain could create negative feelings, as could anything that was unfamiliar and unexpected because it could make a person feel scared and unsure of what to expect. I explained to her that pain and fatigue are two well-known symptoms reported by breast cancer patients due to chemotherapy and that it was important to talk to her doctor about pain medication or other alternatives to handle the pain.

We also talked about the side-effects of the new chemotherapy and how to deal with it, still remembering that it was not the cancer that was making her ill, but a biological reaction to the cancer treatment. The patient said that this information (which we had discussed in the previous session) was the one thing she “grabbed” onto the whole time she was feeling so sick and scared and the fact that she would see me again to talk about the pain and the fear regarding the pain and uncertainty. We talked about the importance of “living” through your emotions and talk about it and share it and put it in a realistic framework (like the cancer- and

chemo framework). In terms of the surgery, which was two months away, she had to accept the anxiety that went with that, but also make a conscious effort to focus on the present – because she could control things that were happening at that point better than things that were going to happen in the future. I have explained to her that everything was about “baby steps”, one thing at a time, and then when something is over, a person could “tick” it off and go on with the next thing.

The session lasted for just over an hour and was a very emotional session. Afterwards she said she felt emotionally much “lighter” for being able to talk about how she felt and she could get everything off her chest. She knew what to expect of the next chemo session which she was on her way to. We made an appointment for the last chemo session three weeks from then. I also reminded her that she could call or text me if she was in an emotional crisis.

#### **FIFTH CONSULTATION: 09/06/2016**

This was the last chemo session (the sixth one). The patient seemed to be so preoccupied with the coming surgery that she felt more anxious than happy. The date of the surgery had been confirmed again on that day for the 11 July 2016 and the fact that she still didn't know what they were going to do during the surgery made her feel scared and uncomfortable. She had already undergone a lumpectomy together with the removal of some of the lymph nodes. She said that she had thought that when the chemo was over, she would feel like celebrating, but because of her uncertainties around the operation and the “not knowing”, plus the bad side-effects of the last chemo, she didn't even think about celebrating.

#### **THERAPEUTIC INPUT**

I explained to her that the different treatment processes (chemotherapy, radiation and surgery) would generate their own fears as well as expectations and emotional- and physical outcomes. Every time she began with a new treatment, there would be new fears and uncertain expectations. We talked about how to cognitively “manage” her thoughts and emotions by taking control through allowing herself to go through the negative emotions, to acknowledge and accommodate it and to share her emotions. She could then ask herself what she could change regarding her circumstances and what she should accept and adapt to. Because

she still felt tired, she had to commit to resting enough during the day, conserve her energy and turn her focus away from constantly having negative thoughts. She also had to allow herself, at the end of this stage of the treatment (chemotherapy) to celebrate it and end it off on a “good” note. She had to rest and relax before the next stage of the treatment started. It made it easier to compartmentalize her treatments and end it off properly. She could finish it by either “celebrating” the end or by ticking it off as finished. By doing that it would feel like it was something with a beginning and an end.

The patient spontaneously started to talk (again) about the very bad negative side effects of the previous chemotherapy and how it made her feel. She said because she was more prepared for what to expect with the next chemo (after our previous session) she felt stronger and could endure the side-effects better. She also mentioned the strong support from her husband and children and how they encouraged her to stay busy and positive. They took turns to take her out and treat her, especially on or before her chemo so that she could focus on something pleasant. I confirmed the positives of her family support and that she should “use” it without feeling guilty and see it as a kind of a “pay it back”, for she had invested many good years in them.

I asked her about her appetite and sleeping pattern: She said that her appetite was relatively good but her sleeping pattern had changed completely now because of the pain. She said the pain in her legs and feet was still very bad but the doctor had prescribed pain medication and supplements that was helping her to a certain extent. Because of the pain and the lack of sleep, she was also more tired than usual. She gave feedback from the previous therapeutic session saying that she constantly did something like knitting or other crafts or did things in and around the house that she liked, like cooking (but not cleaning anymore). She had made peace with the fact that she could not do certain things anymore, but also knew that she would be able to do some of that again. She referred back to that as the “practical guidelines” that we had discussed, and said knowing what to do in certain circumstances, made things easier and less frightening for her.

She then talked again (out of her own) about her emotions and the uncertainty of the upcoming surgery. She said that if she had a choice she would choose a

double mastectomy, because she was scared that the cancer can return to the other breast and that she would have to go through everything again. I let her talk about her emotions regarding the surgery and she wanted to know what would my involvement be with her after the chemotherapy ends and would it be possible to still have contact. I assured her that I would have a session with her before (if possible) and after the surgery and that we would take it from there and decide upon the next therapeutic aims and then plan the follow-ups. After the operation, the oncologist would also decide about whether she was going to undergo radiotherapy or not.

We ended the session on a positive note but without a next set date, for she would have to contact me about the date which she would be admitted for breast surgery.

#### **SIXTH AND FINAL CONSULTATION: 16/11/2016**

The session was scheduled for an hour because she was booked for her next radiation therapy just after our therapy session. A period of five months had lapsed in between the last two sessions because of some practical reasons. We were supposed to see each other before the surgery in the hospital, as in a hospital session, but there were last minute changes to her time and we decided to wait for her to go back to the hospital for her radiation therapy and schedule an appointment then. She underwent a radical mastectomy of the right breast and had to wait for two months for the results of the surgery and to recover properly. After the final results the oncologist had decided on 23 sessions of radiotherapy, which she already had started before this session. Although we did not see each other before the surgery, we had two telephonic contacts where we talked about her fears and concerns regarding the operation. I tried to encourage her to accommodate her fears and anxious thoughts and concentrate on living one day at a time until the surgery and during the recovery stage, making use of the support of her husband and family and using her “new” skills.

The patient looked very well and said that she felt strong and was emotionally in a good place. She said that she had so many things to tell me and that she wanted to start with the surgery because I had not seen her before or directly after it. She said that she had had quite high levels of anxiety before the surgery, especially

before she knew what exactly they were going to do. She said that on a few occasions she had to visit the oncologist because her blood pressure was very high and that the oncologist commented on her anxiousness. She said that after they explained what the surgery was going to involve and what she could expect, she felt more at ease and less anxious about the whole procedure. She said when she was hospitalized, she had experienced “normal” anxiety and her blood pressure was back to normal. She said that at that time she was glad that she understood what “normal” anxiety meant, for she could then handle the anxiety about the surgery and also the time away from the family while she was in the hospital. The surgery went well and she handled the healing process well too, both in terms of the operation itself and her emotions regarding the whole surgery process. In the beginning the worst pain was in her arm and not in the surgical scar. She was still experiencing pain in her arm. She went to a physiotherapist for sessions and did the exercises that the physio had given her. I then explained what lymphedema is and what to expect from it and that it could be present for a long period after the surgery, but it could differ from patient to patient. She would need to consciously accept the current pain and discomfort of the arm and try to implement alternatives to cope with it. I emphasized the importance of going to a physiotherapist and commit to doing the given exercises.

She said that she remembered in her head all the stress handling mechanisms that I had taught her especially the time-management and cognitive restructuring of her thoughts and to express and manage her emotions. She confirmed that it helped her a great deal through her ordeal with the surgery and long wait for the radiation therapy. She also said that the consistent support from her husband and children and her faith and religion literally pulled her through the healing process. She said that she never lost her ability to stay positive and optimistic and kept on believing that she would heal fully. The period she had to wait for the results of the surgery was also tense, but she could put it in the framework of it being normal to be scared when waiting for results. The results of the surgery were very positive and they had not found any more cancer in her breast or lymph nodes. After the final results, they had scheduled 23 sessions of radiotherapy which she already had had 15 of with only eight more to go. The oncologist explained to her that she should use Herceptin at the end of the treatment and that because of this she and

her husband had joined a medical scheme to provide for this treatment. She said that she felt very positive about this medication. I asked her if she understood what type of drug it was – and she said it was something to block the growth and spread of the cancer. The doctor had explained to her that she should visit the hospital for this medication twice a week for six months, that the side-effects would not be so harsh and that her body will be able to endure it.

I asked about the radiation: She said that the positive and pleasant attitudes of the radiation personnel and the relaxed atmosphere helped her to experience the radiotherapy in a positive way. She explained that throughout the whole process of treatment, the way the radiation personnel treated her was the most positive experience and made her feel that she was an important and valued person. This helped her to handle and cope with the radio therapy. She said that apart from the practical implication of traveling to the hospital every day to receive the radiation, she did not experience it negatively and as of yet she did not have any side effects from the radiation. She said she was looking forward to the end of the treatment and that her feelings were especially positive because the therapy would be finished before Christmas. She said that on 7 December it would be a year that she had been diagnosed with breast cancer and that she was really tired and that she could feel she needed a break. She said looking back she had experienced the year as very busy with the constant treatments and traveling to and from the hospital and the waiting periods for either procedures or results. She and her family were going on a long vacation and she was looking forward to it. She now talked very easily about her cancer experience and her emotions, and she believed that this was not only just helping her with her coping process, but also helped other people to cope with their emotional hardship, regardless of what it was. She said that she had a completely different outlook on life than before the cancer and that she felt that she could make a difference in other people's lives.

I asked her about her sexual functioning: She said that there was little change in their sexual functioning because, she thought, they always had a good sexual understanding even before the cancer and that their sexual communication was good. She said that the most positive thing concerning their sex life was that her husband had just, after the latest surgery, told her that the operation and loss of her breast had no negative effect on him and that he felt sexually the same about

her and she should please never doubt that. Although she still felt tired at times, their intimate relationship was as good as ever and they had “normal” sexual activities. Because of her husband’s “soft” approach regarding the sexual side of their relationship she did not feel ashamed about the absence of her breast or even the scar. She said when they did have sexual intercourse she was aware of the hormonal changes in her body and that she made provision for that e.g. lubrication. She felt more comfortable undressing in front of her husband now, she felt comfortable with her body and even allowed him to touch her scars or massage her sore arm. She said because we had talked about their sexual activity right through the therapeutic process, it made the changes in her body more “natural” and less scary for both of them. She appreciated the fact that I had addressed the intimate and sexual side of the therapy. She had not thought that she would ever just talk about sex to anybody. Knowing how the cancer treatments would affect her sexuality she could prepare herself for the changes. She and her husband decided together that for the time she would not have a reconstruction operation and that she felt comfortable with just wearing the breast prosthesis.

I asked her about the role of the therapeutic sessions in her treatment and healing process. The patient answered that before the cancer diagnosis she had not ever known anybody with breast cancer. She had had no previous experience of an illness such as cancer. She revealed that she could cope with all the elements of cancer after she had been informed of all the aspects of breast cancer, the treatments, the side-effects and especially the emotional experiences. She could not have imagined how different it would have been for her if she had not had the sessions because she was so “clueless” about everything. Most of the aspects we talked about during the sessions and the skills that she had learned were not previously part of her frame of mind or practical world. Because of our sessions she could understand what was happening to her step by step and therefore prepared herself for every phase during the treatment process. She said that she was extremely thankful for the privilege to have been chosen for this study because she would not have known to visit a psychologist as it was never specifically mentioned to her during her treatment regime. She explained that the practical advice given to her was the most important aspect of the therapy. An



example of such advice was how to do time management as well as resting during times when she was very tired, without feeling guilty. She also learned to listen to her body and knew the importance of talking to the people around her about her feelings. She felt that the therapy prepared her for all the different and unfamiliar experiences that she would have and that even with the few surprises, such as the side-effects of the second type of chemotherapy, she felt that she had the basic knowledge and know-how to cope. She said that when there was something that she didn't know, she knew that she could ask me the next time, and that made her relaxed. She said another very positive thing for her in terms of the sessions was that she could talk to somebody that was not a family member or even a friend, for there were things that she would not want to burden her family with and that she could share that with me.

To conclude the therapeutic process I emphasized that breast cancer is a chronic illness and that there will be a bridging time to go from being a breast cancer patient to becoming a "normal" person again. It would take some time for her to get used to her "new" status quo. I discussed the fact that after the cancer experience, she as a patient, would feel and think differently than before. As a couple, she and her partner would have a changed perception about each other and about life in general. These changes were not necessarily all negative and could be part of personal growth. She said she could see that there were areas in her personality that had changed. She mentioned that she had become more relaxed about her emotions, especially her negative emotions. She had been sharing these emotions. She had also allowed herself more things in life without feeling needless guilt and that she did not think as rigidly about things as before. I enhanced the fact that changing and growing is an on-going process where applying the needed skills lead to more success in changing and growing.

After an hour I concluded the session by reassuring her that she could contact me any time she felt it necessary to discuss matters concerning her breast cancer or breast cancer treatment and thanked her for being willing to take part in the study. She said that she felt very grateful and privileged for the sessions and being part of a process that might help other breast cancer patients.

## **Appendix**

### **PATIENT III**

Patient III was recruited from a state hospital. After the necessary ethical clearance, as discussed in Chapter VI was obtained, I was granted permission to attend a group meeting of newly diagnosed breast cancer patients with the oncology team at the hospital. The meeting was held in the oncology ward where all the newly diagnosed breast cancer patients would meet at a scheduled date and time. At this meeting the patients were to receive information regarding certain practicalities concerning their chemotherapy appointments and dates, as well as to be familiarised with the place, procedures and the oncology personnel for the period of their treatment. The process of chemotherapy was explained by an oncologist. Patients learned what they could expect in terms of general side-effects and the way forward after finishing the treatment. After the group session the oncologist introduced me to the group and the personnel and briefly explained what my study would be about. I circulated through the group after the information session was over, asking for volunteers. The age interval for my intended study was between 30 and 65 years. I again explained what my study would entail. Three patients immediately agreed to participate in the study. One of the patients only came once and did not return. I scheduled our first appointment for the same day as the patient's next chemotherapy appointment at the hospital. The appointments had been confirmed telephonically the previous day.

#### **DEMOGRAPHIC INFORMATION:**

**Age:** 63 years.

**Marital status:** married.

**Children:** two adult children.

**Highest education level:** grade 10 with extra diploma

**Occupation:** on medical sick leave.

**Diagnosis:** Stage IIB Breast Cancer

**Date of diagnosis:** 13 November 2015.

**Surgery:** none

**Breast reconstruction:** none

**Treatment:**

*Radiation:* none

*Chemotherapy:* had begun the treatment. She had had two of the six chemo sessions. Four sessions left – the date of the last chemo would be on 09/06/2016

*Hormonal therapy:* none

Anti-depressants: none

*Pain medication:* Tramadol 50 mg for pain when needed and Metoclopramide 10 mg for nausea.

*Psychiatric treatment history:* never treated before

## **Diagnoses**

The patient was diagnosed with breast cancer on 13/11/2015 after she had felt a lump in her breast. She first had a mammogram and a fine needle biopsy without any surgery. A date for possible surgery was scheduled on 11/07/2016. This information I obtained from the patient herself.

The diagnosis that was obtained from her medical file: Stage IIB breast cancer, T3 N0 M0. The diagnosis was made on 13/11/2015. The tumour in the breast was 3cm x 3cm and the lymph node was 3cm x 4cm.

## **Treatment plan**

After the fine needle biopsy and the consequent diagnosis of stage IIB breast cancer the patient was started on chemotherapy. She was scheduled for adjuvant chemotherapy every three weeks for a total of six times when she would be evaluated for the most appropriate type of breast surgery and to determine whether she would require radio-therapy.



## **FIRST CONSULTATION: 14/03/2016**

As we agreed, I saw the patient formally for the first time for a therapeutic session on the same day as her chemotherapy appointment at the state hospital. The session was scheduled for an hour. The session took place one month after our first meeting where I had attended their breast cancer group session with the oncology team. We had spoken on the phone only once just to confirm the appointment. We were allocated one of the consultation rooms in the oncology department and although small and impersonal, it was quiet and private and sufficient for our needs. We scheduled our appointments for the same days as her chemotherapies for practical reasons. These included the availability of the patient and the cost effectiveness for her in terms of traveling to the hospital. The patient had already received her first chemotherapy three weeks prior and was scheduled for her second session of chemo therapy after our session.

Before we started with our session, I gave her a short but detailed explanation of what the study would entail, and what would be expected of her as a participant. No complex medical terminology was used. I explained that one of the aims of the study was for the oncology team, including the psychologist, to understand the psychological needs of the breast cancer patient better. This would enable the team to provide a holistic service to enhance the quality of life of breast cancer patients and their families. I explained to her that learning through her experiences during the course of her treatment, could help other breast cancer patients going through the same ordeal in the future. I explained to her that she could at any given time stop her participation without giving a reason or stop answering any questions that made her feel uncomfortable. I gave her the demographic information and the consent forms to read through at home on her own time and discuss it with her family to give her more time to decide whether she wanted to participate in the study and to sign the consent form. I asked her to explain the study to her husband and to ask him if he was comfortable with her participating in this study and if he would later attend a session with her. I gave her the HADS Depression and Anxiety Scale and the Female Sexual Functioning Index – FSFI (see Chapter VI). The two questionnaires were to be filled in at home and I explained to her how to go about to complete it. I assured her of my commitment to the study and to her as my patient and gave her my cell number and

encouraged her to phone me if anything troubled her between sessions that she would like to discuss with me.

After the formalities and the explanations I asked the patient to tell me about her experience with her cancer. She started by telling me how anxious she was when she heard that she had breast cancer, saying that she could remember the exact date and time of the day that she had heard the news. She said that she had been very shocked at that moment and that even for the next couple of days she had felt in a “haze”. She said from there on she only took one day at a time because she didn’t know what else to do. The first time that the reality of the breast cancer really hit her was the day her hair started to fall out after the first chemotherapy. She was receiving what they called the “Red Devil” chemotherapy and that she understood that it was very strong and that her hair had fallen out immediately after the first session. I explained to her that “Red Devil” was the “nickname” for a type of chemotherapy where beetroot extract is an ingredient thereof, causing the red colour (Kapadia, et al., 2011; Opperman, 2015). She said she had “freaked out” when she saw her hair falling out in lumps. She and her husband had decided that he should shave her hair and although it was a very traumatic experience for her, her husband felt that she had known about the hair falling out and should have prepared herself better for it. She said that she felt resentment towards him for his reaction and that they had a lot of stress in their marriage. They were recently married, both for the second time.

She said she felt that at that stage, her husband did not understand what she was going through with the stress of having cancer and the chemotherapy, although in his own way he was supportive of her. She said she had been the main breadwinner before the cancer and still felt that the financial responsibility rested largely on her shoulders which put a lot of stress on her. Both her adult children also relied on her financially. She worked as a health carer and felt that at that stage she could not work with patients, neither physically or emotionally. She said that her work was physically very demanding and that she felt too tired to do her work properly. At the time they were in a financial predicament because she was not earning a salary. The financial stress made her extremely anxious. She said she felt her children were not supporting her properly during that time, but blamed it on their poor relationships before the cancer. She said that they as a family

didn't have good communication skills and hadn't spoken of the cancer yet. She felt the need to talk to them about what she was going through. The patient said she had felt very depressed lately and asked if I could see her husband to explain to him why she felt so emotional about the cancer and what she was going through. She said that she had a lot of problems apart from the cancer and asked if it would be possible to work on that as well. She said she was a diabetic and her sugar was not always under control because she had not been so committed to the diabetic diet and that she would like to learn to control that as well.

### **THERAPEUTIC INPUT**

I let the patient talk freely about how she felt about her marriage and the lack of emotional support from her husband. I explained to her that sometimes by just talking about something that has been on your heart for a long time could be a healing experience in itself. I had the feeling that the patient didn't often speak about her emotions and especially about her marriage and that the catharsis was doing her good. I explained to her that different people have different ways of dealing with pain and that her husband, for example, seemed to be a more practical person when dealing with trauma. An example was the shaving of her hair (before the chemotherapy) where she was more emotional and had more definite and concrete emotional needs, where he had look more at the practical side.

I suggested to her that she should sit down with her husband and try to explain to him how she felt and give him examples of how she would like him to support her.

The patient said that she was very glad to be able to talk about her feelings regarding the cancer and her other personal issues and we ended the session after an hour. We made an appointment for three weeks later at the time of her third chemotherapy.

### **SECOND CONSULTATION: 04/04/2016**

This consultation took place in the same consultation room as the previous session and the order of events were the same. The patient went to draw blood first, and then we had our therapeutic session for an hour. After this the

chemotherapy session would take place in the chemotherapy room down the corridor from our consultation room.

This was the patient's third and last "Red Devil" chemo before she would start with a new chemotherapy three weeks later. Without any prompting, she started talking immediately about her worries and how she felt. She said that she was far more worried about the absence of her children in her life, than the cancer itself. She felt that her children were not interested in her cancer and treatment and were not involved or supportive. She said that this was a very big loss to her. She needed to talk about the relationship between her and the two children, especially her daughter and that she found it depressing that she and her daughter didn't see eye to eye, even in a crisis situation like this with the cancer. There was not a lot of contact between her and her daughter and she felt she could use her help in and around the house as well as her emotional support.

### **THERAPEUTIC INPUT**

I encouraged her to talk about how she felt about her past and especially her relationship with her daughter, and how, by not dealing with it, it could prevent her to deal effectively with her cancer experience in the present. I explained to her the importance of talking about emotions and acknowledging them. I explained that although she could deal with her "old" issues and emotions during our sessions, she should also focus on the cancer and cancer treatment and her emotions and needs regarding that. She could not control her daughter's behaviour, for she was an adult, but she could learn to make peace with that and with their relationship. Instead of just focusing on the negative aspects of their relationship, she should try to involve her daughter in her treatment and illness by explaining to her what she was going through and where she would like her to help and support her. By doing something about the problem, she could feel more in control of her life. She continued to talk about her husband, saying that at the time they were getting along better with each other than they had been at the previous session, but that she still felt resentful towards him about things that had happened in their past. Because of this, she didn't feel that she could talk freely to him about her cancer and how she felt. I explained to her that she could make a conscious decision to accept the things that had happened in the past between her and her husband

since she could not change it. However she could concentrate on changing things now in their relationship. Instead of dwelling on negative thoughts about her marriage, she could try to take her focus away from that and replace it with more positive and constructive thoughts. She could try to concentrate on the realistic and positive things her husband was doing to help her now, such as taking over some of her chores and taking her on long drives to take away her focus from the cancer, instead of just concentrating on the things that he didn't do.

I asked her about her experience of her previous chemotherapy (the third session) and she said that all her hair had fallen out and that she could deal better with it. She was a little bit more used to herself without her hair. She said she was nauseas at the time and had a bad metallic taste in her mouth. She seemed a lot more emotional about the cancer during this session and she was very tearful. When I asked her, she said that she had been crying a lot more and she had been feeling very emotional. She was glad that she would finish her last "Red Devil" that day, but did not know what to expect of the next chemo sessions. She said the doctor had informed her that her tumour was already smaller after the chemo sessions and that it made her feel a little bit more positive. She said she thought about the surgery a lot and that it scared her, especially because she didn't know what they were going to do. I let her share her fears and anxieties about the upcoming surgery and said we would deal with it in the therapeutic sessions. I told her that she should remember that she had an oncology "team" that was supporting her and undertaking the journey with her. She said that she felt so worthy that people (as the oncology team) were willing to help her. We talked about the good news regarding the smaller tumour and that she should allow herself to focus on that. At the end of the session the patient said that she felt relieved about being able to talk about her negative emotions and fears and being able to understand everything better.

We ended the second session after an hour. We made a new appointment for three weeks when she would come for her fourth session of chemo.

### **THIRD CONSULTATION: 25/04/2016**

The patient looked more relaxed than with the previous two sessions. She was scheduled for her fourth chemotherapy and she said she was quite anxious to



start with the new chemo, not knowing what to expect, but hoping that it would be better than the previous three.

She spontaneously started to talk about how she had felt when she heard she had breast cancer. She said she had been devastated by the news and that she immediately thought she was going to die. *“I was very anxious and scared. I was scared of the chemo, not knowing what to expect and was very, very scared to die.”* She said in fact that was all she was thinking about – dying. She was also very scared of the operation: maybe even more scared than of the chemo not knowing when that would be and what they were going to do.

I asked her if she felt that she had the necessary information about the treatments that she would receive and she said that the sisters in the oncology clinic had explained clearly to her, in a nice way, what was going to happen. However if you wanted to know something from the doctors, you had to ask them specifically. She said that they did not explain anything without you asking.

I asked her to what extent the cancer and the chemotherapy was affecting her marriage and sex life. She said that she still felt that her husband was not supporting her the way she would have liked him to and that he did not understand her emotions and fears, but she could see that he was making an effort to help her in and around the house. She said: *“He still doesn’t know how to deal with my emotions.”* They both suffered from chronic diseases and because of that their sex life was not that good and they may have been doing it only once a month. She acknowledged that they have a problem with their sex life. Her husband had consulted with a doctor once before, but it didn’t help him with his sexual problems. She asked me if I would see her husband and talk to him about their sex life as well, for she would like to improve it, saying she thought that maybe they would feel closer to each other. I agreed to see both her and her husband for a couple’s session.

I asked her if she felt depressed or anxious after the breast cancer diagnosis and she said that she definitely does, saying *“but there is a stigma if you feel depressed or if you go to a doctor for depression so I would not share this with anybody.”* She found it difficult to speak about how she felt. She said the day she heard she had cancer and the day of her first chemotherapy was the worst for her.

She was also anxious on that day because of the new chemotherapy. I asked if she was ever treated for depression or anxiety before the cancer and she said that she had felt depressed a couple of years ago when she had had problems with her son, but she had never been diagnosed with depression or had had any form of treatment.

I asked her about her specific side-effects of the chemo at that point. This is what she described:

- she experienced very little nausea and had only once vomited and that the tablets for nausea were helping very much
- She had stomach pain most days and had very bad heart burn
- She said the tiredness was the worst. It was very, very bad and started the same day as the chemo; she was so tired during the day that she fell asleep and then slept badly at night. When she could not sleep at night her thoughts were going around and around in her head, making her very anxious
- Her appetite was poor and she didn't eat well or enough
- Her hair had fallen out after the first chemo session ("Red Devil") and that she felt quite self-conscious and didn't feel like going out in public

I asked her how she felt about speaking to the oncologist about her emotions and sexual fears or functioning and she said: *"No, we don't speak"*. I asked her to explain to me why they don't speak and she said because the sessions were very short and over too quickly. She said that she felt that there was no relationship between her and her doctor.

I asked her if it had helped her to have spoken to a psychologist. She said: *"Yes definitely, especially about my depression and sex with my husband. I haven't spoken to anybody else about it."* She said sex was really not enjoyable anymore and that she and her husband didn't talk about sex or even intimacy. *"We don't talk about the cancer either and I would like to talk about it and how it makes me feel."* She further said: *"If you haven't offered your services in the beginning of the treatment, I don't think I would have ever spoken about my problems to anyone. Every time that I have spoken to you, I have felt relieved especially when I realised*

*that we can work on the problems and that there are ways to deal with it.”* She said she felt that the treatment was more “complete” with our sessions because she knew that it did not matter what occurred, even at home, she could come and discuss it in the therapeutic sessions.

We ended the session after an hour and reschedule for three weeks from then.

#### **FOURTH CONSULTATION: 16/05/2016**

During this session the patient looked drawn and tired. She said that she had started with her new chemo three weeks previously and had slept more or less the whole time. She thought it was most probably because of taking Phenergan which is the medication that prevents motion sickness, and treats nausea and vomiting.

She said she had had very bad side-effects from the new chemo (Taxol) and that the worst side-effects were her fingertips and her feet that felt numb underneath. The soles of her feet were very sensitive and she walked with difficulty. Although she did not vomit, she had a lot of heartburn. She said she was very tired and experienced more and much worse side-effects from this chemo than from the “Red Devil”. Her whole body had been (and was) very sore from the beginning of the new chemo, but it had gotten worse after day three. She said her appetite was also less, but she made sure that she ate properly three times a day. She said that although she was very tired, she and her husband made time each day to do something nice, like going in to town. She said she was so proud of herself because she was still doing all her house work on her own even with the new chemotherapy. The good news was that her daughter had asked her for the first time to take off her wig so that she could see her without her hair. She said that although they had not spoken about her cancer, she saw this as a breakthrough in their relationship.

#### **THERAPEUTIC INPUT**

The patient said she wanted to talk about her daughter and their relationship and I gave her the opportunity to voice her emotions about their relationship and the cancer. This served as an emotional catharsis. We then talked about practical ways to engage her daughter in her treatment and to spend more time together. I suggested that she should involve her daughter more in the treatment process,

such as for instance asking her to come with her to the chemo sessions to familiarise herself with the procedure and to understand more of how the chemotherapy works. I suggested that by going with her mother, the daughter might understand more of what her mother was experiencing. The patient should, from her side, talk to her daughter about how she felt and what she was going through. I suggested that she could make a conscious decision to make peace with how her daughter reacted towards her and her cancer and see it as part of their unique type of relationship. I explained that things between them won't just change because of the cancer since it had been a longstanding difficult relationship. By engaging her daughter in the practical activities of the cancer treatment and talking to her more openly about how she felt, they could begin to build a new relationship that both of them would benefit from. The patient seemed to understand this and felt more confident to talk to her daughter and not have unrealistic expectations of her. She also agreed and understood that she could, from her side, make peace with their relationship and not wait for her daughter to do so first. Instead of agonising over it the whole time she should rather use the time and energy to engage in a quality relationship.

I asked her about the rest of the treatment and she replied that this chemo session was the second last one and after that they would prepare her for her operation. The surgery would be scheduled for three weeks after the last chemo, but she was still waiting for them to confirm the date. She said that she wanted us to talk about the operation during the next session, for she was very scared. She said not knowing what they were going to do make her anxious and uncertain and because of the diabetes she was scared that the wound wouldn't heal properly. She said she was not always committed to her diet and I discussed with her the possibility of taking responsibility for something such as a diet, would make her feel more in control of her illness. She could also apply this advice to the cancer treatment by, for instance, resting more and using her energy more conservatively and making time to engage in activities to enhance her quality of life.

A family member had died of cancer the previous week and it triggered a lot of fear, especially fear of dying. She said that she had such a need to talk about her fears and I gave her time to unwind emotionally. I reassured her that feeling scared and anxious when you were diagnosed with cancer was very normal and

realistic and that she must acknowledge the fear and talk about it. We confirmed again that I would see her husband to explain to him how she felt. We ended the session after an hour, with a new date for the next session (with her next and last chemo).

#### **FIFTH CONSULTATION: 09/06/2016**

The patient began the session immediately by telling me that the following chemo session was her last, but instead of being joyful she was apprehensive about the surgery and that she had just heard from her doctor that the intended date was 11 July. Although the tumour had shrunk remarkably she was still scared of the operation. She was unsure of what the surgery would involve and whether it would be a lumpectomy or a mastectomy. When her last chemo session was over that day, she had an appointment with the surgery department to be evaluated and to get all the information. She asked me if she could continue to see me before and after the operation for she was too scared to do it on her own. I assured her that we would continue with the sessions if it was possible throughout the surgery and afterwards. This alleviated some of her anxiety, for she had appeared very anxious and stressed and said she didn't know how she would have coped without the sessions. Her focus during the session had been on the surgery the whole time and she ever so often returned to the topic. She also had a lot of questions about the possibility of radiation, which she would also only have clarity on after her session with the surgeon. Her main concern about the radiation was whether it would affect her husband in any way. I told her that it was important to ask questions and she should ask the surgeon and oncologist everything that she was unsure of and that she should not be afraid or ashamed to ask questions. I explained to her that knowing what would happen to her and what to expect, would allow her to feel safer and in control.

Apart from her fears about the surgery itself and the uncertainty about that, she said she was worried about her husband alone at home, not being healthy. She was scared that after the operation she would not be as strong as before in order to help him in the way she used to.

**THERAPEUTIC INPUT**



I let her talk about her fears first and explained to her that what she was experiencing is called anticipation anxiety, which means that you are scared of something that must yet happen. This fear could be very draining. I explained to her that every situation has a practical side and a bio-psycho-logical side to attend to. In the case of her husband the problem was more practical in nature and therefore easier to manage. We looked at alternatives e.g. that some other family members, like his grown-up children, could help him with tasks he could not physically manage on his own. She could perhaps prepare food in advance and refrigerate it and he could then just warm it up in the evenings. She could also ask him about his alternatives when she would be in hospital and they could then both make plans for him to cope when she was not there. Instead of just worrying about something, she had to learn to look at it from different angles and make plans to either solve the problem or make it more manageable. She said that the alternative plans had made her feel more at peace with herself and relaxed about the situation at home while she was in hospital. Speaking to her husband later during the session I actually realised that her fears were irrational, for he was capable and willing to look after himself.

I explained to her that when she felt so anxious she should make a conscious effort to relax by for instance doing relaxation breathing. I told her how deep breathing works and that she should relax all her muscles and think about things that made her more relaxed. She could also talk to her husband, go for a walk or do an activity to divert her mind from extremely stressful thoughts.

I also gave her reassurance that if and when she received radiation, the oncologist and radiotherapist would explain all the details to her, but if she felt that there were still things that she didn't understand, she should ask them until she understood.

It would be four weeks before I would see her again. If circumstances allowed I would only get to see her on the day before the operation. I asked her to write down her thoughts, emotions and fears about the surgery and how she was coping in general. She said she liked the idea of keeping a "journal". I also explained to her that writing about practical matters and feelings can be very therapeutic. Again, without enquiring, she spoke about how bad and unexpected the last chemo sessions were and how unprepared she was for the side-effects of

it. At the time she still struggled with pins and needles and excessive pain in her feet and fingers, but she was more prepared for that day's chemo and that the doctor had prescribed pain medication that worked for her. We ended our session after 40 minutes, because the chemo nurse had called her for her chemotherapy and I still had to see her husband. She was reluctant to go, but with the reassurance that I would most properly see her the day before the surgery, she agreed to end the session.

During the previous session we had arranged for me to see her husband and he was in the waiting room while we were first having our session.

### **SESSION WITH HER HUSBAND:**

Although the husband did not sign a consent form, I explained to him the purpose of the research and that his wife had signed a consent form and if he understood that the therapy session also formed part of the research study. They had discussed her participation in the beginning before we had had our first session and he said that he was thankful for the opportunity for her to be part of the study. He also said he felt very positive about that session enabling him to understand his wife and her cancer better.

The husband is a pensioner and came across as a relaxed person. I asked him how he felt about his wife's breast cancer and the chemotherapy and he said it was very traumatic for him, for she was always the healthy strong one, helping him with his chronic disease. He said that after her diagnosis he had done some research on his own about breast cancer and chemotherapy and that he had some degree of knowledge. He admitted that he was far more practical than his wife and did not always understand or acknowledge her emotional reactions.

He said there were days during the chemo that his wife was "normal" and okay where everything went well, but then there were also days when he could see that it was not a good day and then she would be very quiet and withdrawn and was not up to her usual chores. He confirmed the absence of relationships with the children, but said that there were friends that helped with some of the practical issues. He said that his own illness had helped him to understand her better and he thought that he better support her now than in the beginning.

He said that the whole cancer diagnosis and treatment so far was very traumatic for his wife, especially the loss of her hair and the absence of her daughter during the time while she was receiving treatment. They were both worried about their financial situation, but they could work something out at a later stage.

I used the rest of the session to explain to him the side-effects of the chemotherapy and her emotional reactions and fears. I emphasised that breast cancer is a chronic illness with continuous adaptations also in terms of their marriage and sexual functioning. I told him that his wife had confided in me about their sex life and that she has asked me to talk to him regarding that. I explained that even with him having a chronic physical condition, they could still have a healthy sex life. However they would have to make an effort to talk to each other about their sexual needs and desires and make plans together to improve their sex life even if it meant reading books about sex or trying new ways of engaging in sexual activities. He said he never thought he would talk about sex to a “stranger” and yet he felt so relieved that we had spoken about it, because it had been bothering him for such a long time. He said that he was willing to sort out and take control of his illness and would make an effort to improve their sex life. I recommended that he see a specialist (e.g. urologist) to help him with his sexual functioning and he undertook to make an appointment.

I tried to encourage him to communicate more freely and openly with his wife about his and her emotions and that he needed to talk to her and ask her what she sees as support and what her expectations of him were, reminding him that different people have different emotional needs. I also explained to him that the uncertainty of the surgery was causing her a lot of anxiety and that the surgery would have an impact on her emotions and physical strength, but that we will talk about that after the surgery in the next session. I said to him that the focus was on her gaining her strength back after the chemo and preparing herself for the surgery. She would need all the support that she could get. At the end of the session he said that he felt that he knew more and understood better how to help his wife and thanked me for my involvement in the whole process. We ended the session in good spirits.

**SIXTH CONSULTATION: 17/07/2016**



The patient had phoned me to schedule an appointment for a pre-surgery therapeutic session. It was on such short notice we could only arrange an appointment for half an hour. Her surgery would be the next day. She said that although she was scared and anxious for the next day, she was also positive and ready because the surgery was finally taking place and the long wait for the results after the end of the chemo treatment was also over. It had been very scary. She said that she had good news after the chemo concerning the test results. The five lumps were gone and it was not necessary for a mastectomy. They were going to remove some of the auxiliary nodes. However she had a new concern. The anaesthetist said that she had a heart murmur and the function of her heart was less than good because of the chemotherapy. She said she was extremely worried about her heart but her husband supported her very well and she had faith that everything would be going well the next day.

#### **THERAPEUTIC INPUT:**

We talked about her anxiety and fear of the surgery and I reinforced the fact that feeling scared and anxious before surgery was normal and that she didn't have to fight the anxiety but rather acknowledge and accommodate it and work with it. She could consciously focus on her breathing and relaxation exercises during the rest of the day and try to divert her thoughts onto something else like going somewhere with her husband or participating in any activity that would make her focus on something else than the surgery. She said that she already felt better for talking to me and that she and her husband would do something together to divert her attention from the surgery. She said that she had prepared everything at home for her husband (e.g. his pre-cooked meals) for the days that she would be in the hospital and that made her feel less guilty for "going away" and leaving him alone. I emphasized the importance of going to hospital with a calm mood, knowing that everything at home is order and her husband would be able to look after himself. She now had to concentrate on having the surgery and the healing process after it.

We ended the session after half an hour. The patient seemed more relaxed and content and we agreed that she would phone me when she was strong enough or when she started with her radiotherapy in order to book our next session.

## **SEVENTH (AND FINAL) CONSULTATION: 01/11/2016**

This was the first time that I met with the patient after her surgery that had been on 18/07/2016. This extended period without contact was due to practical reasons. She had had to wait for the results of the surgery as well as wait for a date to start with the radiation therapy. She immediately began to explain to me what they had done during the surgery: they had removed twelve of her lymph nodes and found small cancer glands. She said that she had coped relatively well with the operation in spite of the news of the cancerous glands. She was very disappointed about the news of the cancer that they had found because she had thought after the chemo and the good news that the breast lumps had shrunk, she would be cancer free. She said her husband was more stressed than she was, but they had supported each other very well. She had experienced the most pain in her arm and not where the surgery had been done. Her arm was also a bit swollen. She said she had developed severe pain in her one leg and it was making her scared because she didn't know what the pain meant and she was still in the process of making an appointment with the oncologist so that he could explain her leg pain. The uncertainty made it worse and she wanted to know what the pain was.

I asked her about the radiation therapy. She said she was scheduled for 20 sessions and she already had had six. The only side-effect she was currently experiencing was dizziness, but she had no emotional effects such as she had experienced with the chemotherapy. She wanted to forget about the chemo because it had been very difficult for her, especially the "Red Devil". She was still suffering side-effects from the chemo, especially tiredness, and her toes and fingertips were still without feeling. Her sleeping pattern had changed completely and she woke up at 3 o'clock every morning. When she was very tired she took a prescribed sleeping tablet.

## **THERAPEUTIC INTERVENTION**

The patient said although she was trying to be positive, she was very emotional and anxious most of the time before the surgery. She was often tearful. I asked about specific hypothalamic symptoms and she presented with all of the symptoms. I told her that at the end of the session I would ask her doctor to prescribe an anti-depressant for her. The doctor later prescribed Nuzac, 20 mg. I

further explained to her that it often happens that a person develops depression after the cancer treatment because of the treatment itself (the chemical reaction) and because of the tremendous amount of stress and trauma. She said that she did not think of depression as a shame anymore, as she had done before the cancer. She was looking forward to taking an anti-depressant in order to feel better. I explained to her that the anti-depressant takes time to work and that she should use it for at least six months or longer. I recommended that she discuss this with her doctor who would prescribe the anti-depressant. She said that she felt more sensitive and scared than before the cancer but controlled her anxiety better. By learning to focus on the “now” and accepting and controlling her negative thoughts by acknowledging and replacing them with more positive and realistic thoughts, she could feel that her emotions were more manageable and bearable. By means of our therapy, she had learnt to understand her stress better and that there were always alternatives to handle a stressful situation. I let her talk about her emotions for the benefit of catharsis and reminded her of the importance of talking about feelings and giving yourself the chance to work through your emotions. She said that she could feel that when she spoke about her emotions, she felt lighter and better and that she had now identified friends and family with whom she could talk. Although she had had problems talking about her emotions in the past, she now felt much more comfortable in sharing them without feeling ashamed.

She said that for the first time she and her husband were in a much better relationship with each other and that they spoke more about their emotions and what they were feeling. One of the positive things that had come about as a result of the cancer was a better relationship between her and her husband. She felt that after the therapeutic session with him, he had made an effort to understand her and the cancer better and he supported her much more than in the beginning. There was a big change in their relationship, and even their communication regarding their sex life had improved drastically. When the treatment of cancer was completed he would go to an urologist to help him with his illness-related sexual problems. The mere fact that I was willing to talk to him about their sexual relationship made it a much more approachable topic between the two of them. She said that for the first time they were going to do something about their sex life

and that she was looking forward to it. I advised her to identify positive things in her life and relationship with her husband and recognise it and enjoy it and also use it as reinforcement when things were difficult for her. It was always important to realise that even in difficult times there could be positive and good things happening and that you could choose to enjoy it. This would only be possible if you lived in the here and the now and concentrate on what was happening, accepting your feelings and thoughts without being judgemental or too harsh on yourself.

We talked about taking control over situations that were very stressful, such as the extreme pain that she was experiencing at the time by taking some sort of action. An example would be to persist in phoning the hospital or going there to make an appointment to check it out. By taking action and making plans you would feel less of a victim and more in control of yourself and your situation. If there was something that you did not have knowledge about, you could ask somebody who would know. I advised her that she should use her support system which included the oncology team at the hospital. We talked about the importance of her keeping busy without tiring herself, choosing her activities wisely and prioritising important tasks. I suggested that she and her husband could get involved in activities together like taking walks and going on coffee dates to improve their intimacy. They should keep on talking and supporting each other. She could also make an effort to get involved in doing crafts or maybe join some of their church activities to interact with other people.

I summarised our therapeutic process by emphasizing the reality that after a diagnosis of cancer and cancer treatment there would be permanent changes in her life such as, for instance, the way she would perceive life and herself as a person and a woman and her relationships. I explained the losses that she might feel and that she should give herself the time to grieve and accept and also to embrace that which she still had left. I told her that she should learn to acknowledge her emotions when they were negative and not be scared of being scared. With the chronicity of the illness, new challenges would come and she would have to “tackle” them too. I told her that every time she needed to go for follow-up sessions and tests because of the cancer she could expect to feel anxious. She should allow for it and put it in the framework of her cancer and keep

on reminding herself that it was normal to feel stressed in such a situation. I reminded her that she had learnt new coping skills to handle stress and stressful situations and to use and develop them. If she felt depressed and it did not get better, she should make an appointment with the hospital to see somebody to treat the condition. She should always remember that conditions like depression and anxiety are treatable.

At the end of the session the patient thanked me for the sessions saying that she had never before seen a psychologist and did not even know what they did but feels so blessed to have been able to see me and had had the opportunity to understand not only the cancer better, but also herself, her husband and even her daughter.

#### **PATIENT IV**

This is a private patient who was referred to me by a clinical psychologist who knew about my study. The psychologist contacted me to ask whether I could see this person as a study participant because she needed to be seen by a psychologist but did not have the available funds to participate in a psychotherapeutic process. The psychologist thought that she was a good candidate for the study because of her cancer-related emotional distress and impairment. The psychologist had first explained my research study to the patient asking if she would be willing to participate in such a study and after her permission was obtained the psychologist gave me her contact details. I contacted her telephonically and gave her a bit of background regarding my study and what would be required of her if she wished to participate in a psychotherapeutic process. She said that she would like to participate in the study and that she was ready for psychotherapy. We scheduled an appointment for her to come and see me in my private practise.

#### **DEMOGRAPHIC INFORMATION: PATIENT IV**

**Age:** 49 years

**Marital status:** in a long term permanent relationship for ten years, no children

**Number of children:** none

**Highest education level:** four year degree and higher diploma

**Occupation:** full time occupation in higher education

**Diagnosis:** Stage III Invasive Duct Carcinoma

**Date of diagnosis:** September 2015

**Surgery:** Lumpectomy and removal of two lymph nodes on 15/09/2015

**Breast reconstruction:** none

**Treatment:** *Radiation:* thirty sessions in six weeks – ending 24 March 2016

*Chemotherapy:* Twelve sessions over three months – ending February 2016.

*Hormonal therapy:* none

*Anti-depressants:* Epilizine, Nuzak, Wellbutrin and Pax.

*Pain medication:* none

*Psychiatric treatment history:* She's been diagnosed and treated for major depression, with the first diagnosis in 1991.

## **Diagnosis**

The patient had felt a lump in her left breast nine months prior to her first visit and went to her general practitioner. She first had a mammogram and then a fine needle biopsy. A diagnosis of breast cancer had been made, after a lumpectomy and the removal of two lymph nodes. She was diagnosed with Gr. III Invasive Duct Carcinoma (in situ) - 28mm DCIS. Triple negative with clear margins. This information was obtained from the patient herself. I did not have access to her medical file, nor did I have interaction with her oncologist.

## **Treatment Plan**

She had surgery first (very soon after the scanning and diagnosis). She started with chemotherapy after lumpectomy and received three sessions of the "Red Devil" chemo therapies every three weeks, plus 9 more chemo therapies once a

week, every week. She was given one week off in between the chemo and the radiation therapies and had had 12 sessions of radiation therapy. With our first consultation she was two months post treatment and in remission.

### **FIRST CONSULTATION: 25/06/2016**

I saw the patient for our first consultation session in my private practice which met all the criteria for a therapeutic environment as it is comfortable and private. The session was booked for an hour and thirty minutes. The patient was from out of town and had requested that, if possible, we could schedule longer appointments at a time.

After the formal introduction, I gave her a detailed explanation of this study without using complex terminology of what this study entails and what would be expected of her as a participant. I explained that one of the aims of the study was for the oncology team, including the psychologist, to understand the psychological needs of the breast cancer patient better in order to provide a holistic service to enhance the quality of life of the breast cancer patient and her family. I gave her the demographic information and the consent forms to read through on her own time and to discuss it with her family and partner so as to give her more time to decide whether she wanted to participate in the study and then to sign the consent form and bring it with the next session. I explained the two questionnaires - the HADS Depression and Anxiety Scale and the Female Sexual Functioning Index – FSFI (which was explained in Chapter VI) and asked her to complete it when she had time and to bring it back the next session.

After the formalities and explanations I asked the patient why she had requested to see a psychologist. She replied that she had had a very long history of depression from a young age and that she tended to become easily depressed and anxious. She said she had noticed that while she was undergoing the cancer treatment, especially chemotherapy, her symptoms of depression had increased noticeably. She said in the beginning she was more scared of becoming depressed again because of the breast cancer diagnosis and treatment than she was for the cancer itself! She explained to me that she had seen psychiatrists and psychologists over the years for treatment for her depression, receiving medication and therapy. She said she was aware of the fact that she could

become depressed because of her history, and that she contacted her psychiatrist immediately after she was diagnosed with breast cancer to ensure that her psychiatric medication was effective for the extra stress from the cancer. The psychiatrist prescribed Epilizene, (an anti-epilepticur), Nuzac and Wellbutrin (both are anti-depressants) and she was on this medication throughout her cancer treatment until that point. She said that after the cancer diagnosis she felt very strongly that she would need to see a psychologist, but as a private patient, she could not afford to because of all the expenses the cancer treatment had caused. She said that she was very relieved when she heard about this study and that she could speak to somebody about her emotions regarding the cancer and her fear of developing depression again. She said: *“if I could have seen a psychologist from the beginning of the cancer, it would have made a huge difference and I would be able to have controlled my emotions better”*. She said that if she could have seen a psychologist her chances of relapsing would have been smaller. She explained that apart from the depression she also had high levels of anxiety. During the session I experienced that the patient had a great need to talk to somebody about how she felt and what she went through during her cancer treatment which had only ended two months prior. She said that everything regarding the treatment was still very vivid in her thoughts and she was reliving it every day.

I asked her how she felt when she was diagnosed with breast cancer and she said that it was very traumatic for her although she had expected breast cancer after she had felt the lump in her breast. She said everything progressed very quickly from the time she had felt the lump and began the treatment and from then on everything just snowballed. She said that although she was extremely emotional during the treatment, she felt even worse now and in need to see somebody to talk to about her “deepest feelings” and to help her to put everything in perspective. The patient was very tearful during the session.

I asked her about the side-effects of the chemo therapy. She said she had a lot of bad biological and emotional side-effects and the chemotherapy was “relentless”, with the “Red Devil” three times every third week and nine “other” chemo’s every week for nine weeks. She described the side-effect of chemo as follows:



- The first thing that happened to her due to the chemo therapy – the “Red Devil” - was her hair that had all fallen out as well as her body hair, and that it was quite a weird experience for her. She was never nauseas and never vomited.
- From the very beginning of the cancer treatment, the biopsy, surgery and then the chemotherapy, she had been scared and afraid and had a lot of anticipatory anxiety before procedures. She explained that the whole process of administering the chemo were very intimidating and freighting to her.
- Her sleeping pattern had changed immediately from day one and she suffered from insomnia, but she was not sure if it was because of her mood and depression or if it was the cancer treatment.
- The emotional impact of the breast cancer diagnosis and the chemotherapy was the worst for her. She said she felt depressed from the beginning of the chemo and could “literally feel how the depression had worsened every day”. She described it as the severest form of depression that she had ever had. The patient said for the whole four months that she had received chemotherapy she felt physically ill and emotionally upset. It was because of this that she felt the need to see a psychologist and although her oncologist had suggested her seeing a psychologist, she could not afford it as a private patient. She said although she was on a combination of anti-depressants, she also needed to talk about, and understand her emotions and fears. She had never before been in a similar situation and felt a lack of specific skills to deal with her cancer.
- She said another side-effect that she experienced a lot was tiredness and it contributed to her negative feelings during the duration of the chemotherapy. It was very important for her to function at a very independent and high level and not be dependent on other people and that the tiredness had confronted her with a vulnerability which made her need assistance from other people. She said that she had very high expectations of herself and therefore pushed herself very hard to perform at top level, whether it was at home, or in social relationships or at work. During the

chemotherapy, she felt very tired and listless and lethargic which was very atypical of how she usually performed.

- She said that she had gained a lot of weight throughout the cancer treatment, but that she was not sure if it was because of the treatment itself or if it was more because of comfort eating because of her depression. Gaining weight also played a role in her depression, *“it makes me even more depressed if I gain weight”*. She said that she tended to be an emotional eater when under duress. The weight that she had gained was just another stressor that she had had to deal with and would like for us to make it a therapeutic goal for the future to talk about her weight and self-image and self-confidence.

We ended the session after an hour and thirty minutes. The patient talked very easily, eagerly and without any prompting. The session served as an emotional catharsis for her, while also providing me with sensible and applicable information. We scheduled the next appointment for the following day (because she was in town for the two days and it was more practical for her) to continue with the above process. We scheduled a one hour and thirty minute session.

## **SECOND CONSULTATION: 26/06/2016**

The patient started the session by saying that the session of the previous day had done her good because she could talk about all her emotions without keeping anything back. She spontaneously started to talk about the negative side-effects of the chemo-therapy. She said that apart from the tiredness and emotional turmoil that she had experienced during the chemotherapy, the chemo-fog (she used the terminology) was a very bad side-effect. She felt very stupid and slow and not intelligent at all during the chemo treatments. She said her work entailed a lot of concentration and focusing, and in the beginning of the chemotherapy, she had been constantly scared that she would not be able to do her work properly. She said she relied heavily on her intellect. She said she saw herself as very career orientated and driven and her work played a large and important part in her life and identity. She experienced her employer and colleagues as very accommodating and lenient which made it possible for her to have worked

throughout her whole treatment and she had only taken off the day on which she received the chemo and the day after that. She said the support from her colleagues was very positive and encouraging and the fact that she could carry on working, made her feel safe and secure. It kept her busy and helped to direct her focus away from her cancer and anxiety. The patient said that during the cancer treatment her finances were a big concern, because she was a private patient and had to pay for the treatment herself. She said she had never realised how expensive cancer treatment was and therefore was even more scared of not being able to do her job and then ending up losing it.

I asked her about the radiation therapy to which she replied that it was not bad at all, apart for the effort to go in to the oncology rooms every day. She said to her it was more of a practical issue than a biological or emotional issue. She said even her skin had never been sore or overly red and it had healed quickly again. I asked her if she ever experienced any pain and she said in terms of her cancer she had little pain but she had “difficult” arteries to insert a needle and that every time she had to receive chemotherapy she had intense anticipation anxiety because she was scared that it would be painful.

I asked about her menstrual status before the cancer treatment. She said she was still completely pre-menopausal before the cancer and chemotherapy, but her menses had stopped after the first chemo. She suspected it was most probably more stress related than chemo related because she was so stressed and anxious all the time. She said that during that time she also had had hot flushes but couldn't think of any other menopause-related symptoms. She said that she had had her period again the previous month (one month after her last treatment) and that her PMS was very bad. She thought it was her depression that was returning and that she was very relieved when realising that it was (only) PMS. She said she was used to severe PMS and she would rather handle it than a full blown depression again.

**Therapeutic intervention.** I explained to her the psychological impact of a cancer diagnosis on a person, even on somebody who never had depression or anxiety before and that it was not abnormal to either develop depression or anxiety or be scared of developing a mood disorder. I said to her that the fact that she had

prepared herself for depression and anxiety by taking extra measurements, e.g. phoning the psychiatrist and making an appointment to check her medication was very positive to me. I told her that I experienced her as somebody who takes responsibility for herself and her treatment. I also told her that, although she felt she should have seen a psychologist during her cancer treatment, it was not too late now for she can still express her emotions and that she could learn new skills to handle herself and her new situation. I said to her that, because she knows the symptoms of depression and anxiety, she could manage the symptoms with the help of her psychiatrist and psychotherapy. She should remember that depression and anxiety are treatable conditions. I explained to her that her negative thoughts about developing depression and her constant thoughts roaming around in her mind made the depression and anxiety worse and she could try to focus away from the roaming thoughts and create more positive and realistic thoughts that could make her feel better. I explained to her that putting so much pressure on herself in terms of her work could also contribute to her depression and she had to accept that she still had less energy than before the cancer and should learn to manage her energy and prioritise not just at work, but also at home. I asked her about her partner and family in terms of support and she said that she had from the beginning gotten very good support from her family and friends and also from her partner. We discussed for her to put aside time every day, even at work, to take a proper break and rest so that she could preserve her energy and to rest more over weekends, and make time for activities that made her feel better and to involve her partner in her healing process as well. She asked if it would be possible for me to also see her partner to hear what he had to say about her cancer.

I asked her about her relationship with her oncologist and she said that she had a very good relationship with her from the very beginning. She explained that she and her oncologist had very open communication and she felt that she had provided her with enough information about the chemotherapy and side-effects. She was also given articles and pamphlets to read on cancer and cancer treatment. She said that, although she was “academically” well prepared and well-informed, the chemo therapy was still a huge shock on her system and was not prepared for the emotional impact of that. She said that her oncologist had asked

her whether she would like to see a psychologist, but because she did not have a medical aid, she could not afford to see both a psychiatrist and a psychologist. She said it made sense to her that a cancer patient should see a psychologist during the treatment of cancer for the emotional impact is just too big for any person to carry on her own, even with good support from friends and family.

I asked what she perceived as her biggest losses regarding the cancer and cancer treatment and she said: *“the treason of my body. I have realised that you cannot trust your own body which was an eye opener to me, I really felt betrayed by my own body.”* She said that when you have cancer you don’t have any control over your body anymore or what is happening to it, *“all of a sudden other people got to make decisions over your body”* and especially for somebody like her, which was extremely private and independent, the fact that she was so vulnerable and defenceless, was a major loss for her. She said that, looking back now, she thought that if she was given a little more time to think clearly about the treatments and their effects and side-effects, or had spoken to a psychologist to settle her traumatic reaction, she would have felt more involved in the whole process of decision-making. She also found cancer to be an extremely busy illness, saying that when you are in the middle of it you don’t know how to juggle everything with the treatment, the work and the relationship. The “busyness” of the treatment had put a lot of stress on her, especially because she always wanted to be in control and handle everything on her own as well as helping other people. I agreed that cancer is indeed a “busy illness” and that a lot of unfamiliar things happen simultaneously which can also contribute to a person’s distress. She said another big loss was her financial losses because of the lack of a medical aid and that she was still recovering financially from the cancer.

I asked about dying, and she said that she was not afraid of dying at all, but that her partner did not like to talk about dying. She thought that they needed to talk about it and when we had a session together we should touch the subject of death. She said she sees death as a practical component of life which has to be talked through with your loved ones. She felt very comfortable about talking about death.

We ended the session after an hour and a half and made another appointment in four weeks' time. Although I thought that we should see each other sooner because of her depressive state, she only came to town every second or third weekend because of her financial status. I gave her the reassurance that she could phone me, or leave a message any time in between the sessions if she had a crisis or needed to discuss something urgently.

### **THIRD CONSULTATION: 6/07/2016**

The patient looked very emotional and teary. She started talking immediately about the chemotherapy again. She said it had been such a bad experience for her and that she had had bad and negative memories of that. She said during the chemotherapy she fell apart and that even the medication the doctor had given her for the side-effects of the chemo had made her ill. She said that the whole four months that she received chemo-therapy she had felt ill and miserable. She had had one blood transfusion during the period of the chemotherapy and that the idea of receiving blood was very negative to her and she had not coped well with that. Looking back on the chemo and the tests and the blood transfusion she said that she had experienced it as a very busy, time consuming and stressful process and she also realised that she could have coped much better if she had had the help of a psychologist. She said that she felt much more emotional after the treatment had ended as during the treatment. It had already been three months, and could not understand why she was feeling so emotional then. She felt that during the treatment, although she felt emotional, she didn't have the time to dwell on the emotions for there was no time between the chemo sessions and the blood drawing sessions and appointments with the oncologist and going back and forth to work to have focussed on her depression and anxiety. She said recently she felt very down and had been crying a lot (she was also crying a lot during the session). She was still experiencing side-effects of the cancer treatment and wasn't prepared or expecting it to last such a long time after the end of the treatment. She said that at the time the tiredness was the worst. She felt tired all the time and had very little energy to do anything else, she said she went home and to work and that it was all. She said because she had gained so much weight she really wanted to start exercising again, but just didn't have the energy or the

drive to begin. She said her weight bothered her a lot and that she felt unhealthy and uncomfortable. She said that gaining weight contributed to her depression.

She said that the breast cancer diagnosis and treatment had been an extremely radical experience for her and that the most important thing that kept her sane during her treatment was going to work. She said that she had tried to go in every day, even on the days that she felt sick, just to stay busy and be surrounded by people. Because she was also financially dependent on her salary, she could not afford to jeopardise her work. She said that being so involved in her work was one of her coping skills.

### **THERAPEUTIC INPUT**

Because the patient felt emotional on that day, I gave her time to talk about her emotions. I explain to her that often negative and depressive emotions develop or intensify after the end of the cancer treatment and that going from a cancer patient to being a “normal” person could be challenging, and it would affect her mood. I told her that I was concerned about her emotional well-being because she seemed more depressed than the previous time I had seen her. I explained to her that some of the symptoms of depression could be the same as the side-effects of the chemo, especially the tiredness and lack of energy, low libido, problems with memory and concentration, disturbed sleeping and eating pattern as well as a depressive mood and that these “double” symptoms could be quite overwhelming. I asked her if she was having suicidal thoughts and she convinced me that at that moment in time she didn't think about suicide. I explained to her that it was important to manage her depression symptoms through her medication and coping skills and support from her partner and family. I also assured her that there were always alternatives when managing depression, for instance admittance to a hospital or a clinic specialising in mood disorders, changing her medication (as prescribed by the psychiatrist) or increasing the therapeutic sessions.

I explained to her the importance of acknowledging her emotions and talking (or writing) about it and consciously engaging in a grieving process, working through all her losses. The impact of the cancer experience, losses and new adaptations was often only a reality after the cancer treatment and could be very overwhelming and needed to be recognised and worked through.

We talked about how she felt about her weight and eating habits and exercising and she said that she needed a session on its own to work on her self-image (we made it a goal for the next session to work on this). I explained to her the benefits of losing weight in terms of her self-esteem and also sexual self-esteem, but that she would have to make a conscious decision to go on a healthy diet. I suggested to her that she might find it helpful to contact a dietician and to start a diet plan with professional help. I explained to her that it is always helpful to start with baby steps, especially exercising. She could start walking around the block once every day and involve her partner in this and as she got fitter, she could walk farther. So even if she felt tired, she had to take the first step and start walking and if she was too tired during the day she could start over the weekend during the time of the day that she felt best. She said that there was a place where she could walk at her work place and that she could walk there over her lunch time. I explained to her that by talking about things that bothered her and making plans to change it would already make her feel more in control and less of a victim. I explained the importance of prioritising her activities so that she could have time (and energy) to do things that she enjoyed and would contribute to her quality of life. I described the importance of focusing on the present and especially focusing on her thoughts. She should identify negative and destructive thoughts and try to focus on new and more realistic thoughts.

When asked, the patient said that although she and her partner did not discuss the sexual impact of the cancer and menopause they always made an effort with their intimate relationship. She said they do not have an active sex life and would like to hear what her partner was saying about their sexual relationship.

We ended the session after the scheduled hour and a half and rescheduled (for her and her partner) one month from then for a follow up session with the aim of both getting information from the partner and to explain certain matters concerning their relationship.

#### **FOURTH CONSULTATION: 20/08/2016**

The patient and her partner came together for a couple's session that the patient had suggested. (The patient had then been finished with her treatment for five months). Her partner had not given written consent, but was fully aware of the



research study and that the partner was participating in the study. He felt very thankful that there was a place that his partner could talk about her emotions. I explained what he could expect from the session and whether he felt comfortable about it. I asked him to tell me about his emotions regarding his partner's cancer and the cancer treatment. He said that there were times that were very tough for both of them, especially with the tiredness and constant depression. He told me that the emotional side was far worse than the medical side, although he thought she coped relatively well throughout the treatment. He was not used to seeing her enduring so much turmoil and felt sorry for her, not always knowing what to do or how to help her.

The patient then started to talk about how she was feeling, and said that she felt very depressed, much more than the previous time that I had seen her. She was also very tearful and looked extremely depressed. I used the DSM 5 criteria to assess her symptoms for depression and she presented with all the symptoms of depression. I suggested that she should make an appointment to go back to her psychiatrist and make sure that her medication (Wellbutrin, Epilizene, Pax and Nuzac, 20 mg) was still effective.

### **THERAPEUTIC INPUT**

I again explained the alternatives in treating depression, for example to be hospitalized in a clinic for mood disorders, altering the medication through her psychiatrist and more therapeutic sessions. I again emphasized that depression is a condition that is treatable and explained to the partner the relationship between depression and cancer treatment especially chemotherapy which can cause a chemical depression. I also explained to him that somebody like his partner, who was predisposed to a mood disorder, was more prone to developing depression during cancer treatment or afterwards. I wanted him to understand this and that there were interventions to relieve the symptoms of depression such as medication (which they were familiar with), therapeutic techniques, or as mentioned above, even hospitalization. I explained to them that it was important to acknowledge and accept a condition (in this case depression) as part of the specific situation and to take step-like measures to handle it - always starting with the practical side, such as making an appointment with the psychiatrist and sorting out the medication and

plan therapeutic goals with the psychologist regarding the symptoms of depression. By doing this it would give them the feeling of gaining control of the situation. I emphasized the fact that it was not abnormal to develop depression or anxiety during or after cancer treatment.

The partner said that he felt that if she had somebody to help her through the process of the cancer treatment she would have coped better, especially because of her background of depression, but that he also understood that they could not afford both a psychiatrist and a psychologist. The patient (out of her own) said that she did not know how to proceed from a cancer patient to a “normal life” again. She also said that she had gotten used to the cancer “schedule” and the interaction with the oncology team and co-cancer patients. It made her feel safe and secure. She didn’t exactly know where she belonged then, although she knew she was in remission (she was going for her sixth month check-up the following month), but because she still experienced side-effects of the treatment she still felt that she was “busy” with cancer. She said her worst symptoms were the persistent tiredness and lack of energy, and lack of concentration and memory, which again contributed to her feeling of depression.

### **THERAPEUTIC INPUT**

I explained to the couple that there could be permanent changes after cancer, not only for the individual but also for the couple and that they needed to understand these changes and to develop and adapt to, a new post-cancer status quo. The changes due to breast cancer could be biological, such as her breast shape and scars and the changes in her oestrogen levels, but could also be psychological, such as a change in their outlook on life from a different angle and even perceiving each other differently. By talking about the changes and challenges, or writing it down together, they could then decide how they were going to attend to it and incorporate it in their relationship together. It was important for the individual and the couple to work through a grieving process through acknowledging and facing their emotions and making peace with it and consciously accepting their new situation. I also explained to them that all changes were not permanent e.g. the tiredness and the reduced short-term memory would get better with time and they only had to adapt to such problems temporarily and that all changes were not

necessarily negative. I also told them that by using constructive mind control, and new behaviour, they could adapt to the new situation in a positive way. Communication was a good way to start – to ask your partner what he/she wants in a specific situation or how they are experiencing you, instead of expecting your partner “to know” what you are feeling or needing. It was also imperative to talk about emotions and not to feel that you had to be “strong” all the time for your partner’s sake. Showing your emotions is not a sign of weakness, but a commitment to understand and support each other. They both said that they felt closer to each other after the whole cancer episode and that they were more relaxed and at ease with each other and they looked at their relationship and each other with different eyes.

I asked them about their sexual functioning. Both of them were comfortable speaking about their sexuality and the patient answered that their sex life was not good even before the cancer treatment because both of them suffered from a low libido, but that they had never regarded it as a problem for they had a very good intimate relationship. She said that, having said that, she would like to talk about their sex life when both of them were there because she really thought they could improve it and that it would enhance and strengthen their relationship. I explained to them the impact that depression and anti-depressive medication and menopause could have on their sexual functioning, especially on their libido or biological sex drive. It was imperative to understand that the low libido had nothing to do with their relationship or feelings for one another, but it had rather to do with the biological component of the illness. The biological implications of menopause, apart from the mood swings and emotional reactions, were that foreplay might take longer and require more effort and using vaginal lubrication or a moisturiser was necessary to counteract the lack of vaginal lubrication and discomfort. Some of the practical alternatives, especially because the patient felt uncomfortable with the surgical scar, were for her to wear something like a camisole to bed to hide the scar or to wear the prosthesis bra. They had to talk about what alternatives they felt comfortable with and use it (e.g. watching sexual movies together or using a vibrator for extra stimulation). We also talked about setting up a time table for sexual activities during the time of the day (or night) when the patient felt less stressed and tired. They both agreed that more sexual activities would enhance

their sexual and overall quality of life and they agreed to commit themselves to using creativity to improve their sex life. They were both very liberal regarding sexual activities and had no problem with more flexible thoughts and actions concerning their sex life. I explained to them that the fact that they were intimate the whole time would make it easier for them to regain their sexual activities, but that developing a new and more active sex life would take time, effort and creativity. The patient mentioned her weight and the scar again and said it inhibits her to relax sexually, but her partner said that it does not bother him at all and did not affect his sexual attraction toward her.

We ended the session after an hour and fifteen minutes and the patient asked if we could talk about her self-image the next session. We scheduled another hour session for one month from then.

#### **FIFTH (AND FINAL) CONSULTATION: 25/10/2016**

Due to practical reasons, the patient had postponed the session with another month, so there was a two month period in between the last two sessions. The patient looked distressed and tearful. I asked about a consultation with her psychiatrist and medication and she answered that she was in the process of making an appointment with the psychiatrist and that she was diligently drinking her anti-depressant medication every day. I strengthened the idea that a major depression could take time to get better and that a conscious and active involvement (medication and therapy and interventions) would bring positive results. She said that every time we spoke about her depression and that she could do something about it, made her feel stronger and less “abnormal”. She said knowing and understanding the influence of depression on her life and relationship also made her feel more positive about herself and her relationship and even her lack of sexual functioning. She also understood that some of her symptoms like tiredness and lack of energy and drive and even lower sex drive and negative emotions could be part of both her depression and side-effects of the chemotherapy. She felt that she could manage it instead of just feeling like a victim of herself and circumstances. Our aim for the session was, by her request, to work on her self-image, both in terms of self-confidence and body image as related to her sexuality. I asked her what she thought was degrading or influencing

her self-image and she said that there were a couple of elements “working against” her self-image and confidence. The most important one was her weight gain and changed body due to the surgery and cancer. I explained to her the importance of firstly making a conscious decision about losing weight and that the next step after making a “formal” decision was to start with a commitment to changing certain patterns of eating and to use or involve the right professional people in this process. Firstly she could schedule an appointment with her psychiatrist (as already mentioned above) to (also) discuss her anti-depressant medication, because some of the medication could elevate her appetite and enhance her chances of gaining even more weight. She could also involve a dietician to get a proper diet plan to make sure that she lost weight in a healthy way and with the necessary support and encouragement. She explained that the breast, where she had the lumpectomy, is now different from the other one and that it made her self-conscious and that even her clothes looked different on her. I asked her about breast reconstruction and she said that although she had never thought about it in the past, she was considering it. She said it would have to wait until a much later stage. We talked about a proper grieving process (facing and going through her emotions) regarding her breast cancer and accompanied losses and she said that she needed to face it in a proper way through talking about it and accepting it. We then discussed that in the mean time she had to make peace with her “different” breasts and maybe even change her clothes to hide her breast deformity and to emphasize other body parts that she felt more comfortable with. We talked again about exercising and I referred back to a previous session where we had discussed her taking a walk during her lunch hour at work just to start getting more active and getting in a habit of exercising and allowing herself to invest more in herself without feeling guilty. She should look at the weight she gained as part of the whole cancer journey. Her severe depression should serve as a reminder that, with the help of other (professional people), she could take control of the situation. She also agreed that by losing weight she would feel more sexual and confident to participate in sexual activities and that if she lost weight she might even have more energy for sex. She said that she wanted to give a bit of feedback from our previous shared session with her partner, that they had started to improve their intimacy even further and that they had participated in activities with much more touching and sexual closeness without necessarily being

sexually active. She said that it made her feel better about herself and as a couple they felt much closer to each other.

She said the lack of self-confidence also influenced her job performance. I explained that she should concentrate on identifying irrational and untrue thoughts regarding her self-image e.g. "I am not good at my job anymore" or "I can't remember as well as before the cancer", she should then substitute these thoughts with more true and realistic thoughts such as "the cancer did not change my intellect or ability to do my job" or "the cancer did not take away my qualifications" or "even if I struggle with my short term memory, there are ways to help me with that". By keeping on telling herself that she was good and able enough and had the ability to grow, would help her "believe" in herself again and this way she could "act it out". Because her self-image and self-confidence had decreased over the years because of her weight problem, depression and also recently because of the breast cancer, she had to allow for sufficient time to improve and develop a "new" self-image and confidence. She also had to accept that due to the cancer treatment, her body would be changed biologically and factors like menopause would also affect the working of her body. She could focus on things, activities and thoughts that would make her feel better about herself. She said that she could take up her hobbies again and actualise herself by means of this, instead of thinking about how "bad", passive and different she was. She said that by talking it through with me in therapy, her mind already worked in the direction of what she could and wanted to do again. She referred specifically to those things she had done before the breast cancer that had always enhanced her self-confidence. She said that having plans (like making appointments with her psychiatrist and dietician) and begin with exercising and new thoughts about herself made her feel more positive already. She thought that when she felt confident about herself as a whole person, she could maybe even think about changing her job or studying further.

I concluded the session by thanking her for her participation in this study and she said that the therapeutic process helped her so much and that she felt much more "clever". She said she understood and could handle herself much better in terms of the depression, especially now after the cancer. She asked about extending her sessions after the research study, for she was in a process of applying for a

medical aid, which I supported, saying that participating in psychotherapy is always a beneficial and rewarding process, especially in a chronic situation such as breast cancer.

We ended the session on a good and positive note.

## **PATIENT V**

This is a private patient who was referred to me by an oncologist working in a private practise who knew about my study. The patient asked the oncologist during a follow up consultation to be referred to a psychologist to help her with her emotions regarding her breast cancer and her relationship with her husband which was stressful at the time. The oncologist told her that I was a clinical psychologist and that I was busy with a research study regarding breast cancer and whether she would be willing to participate in this study. The patient replied that she would be willing to participate in a therapeutic process. The oncologist provided me with her contact details and I phoned to schedule an appointment. During our telephone conversation I explained in short what the study was about and what her role as a study participant would entail. An appointment was made for one week after the contact.

## **DEMOGRAPHIC INFORMATION**

**Age:** 34 years

**Marital status:** married

**Children:** one pre-school child

**Highest education level:** diploma in financial management

**Occupation:** full-time occupation in finances

**Diagnosis:** Stage IIA Ductal Carcinoma

**Date of diagnosis:** 18 March 2014

**Surgery:** double mastectomy (17/11/2014). Complete hysterectomy (June 2015)

**Breast reconstruction:** completed

**Treatment:**

*Radiation:* fifteen sessions. Ending in April 2015

*Chemotherapy:* six sessions - with three of it "Red Devil"

Chemo over a period of five months - ending October 2014

*Hormonal Therapy:* Tamoplex, still busy.

*Anti-depressants:* no anti-depressant, or any treatment for depression or anxiety before.

*Pain medication:* none

**Diagnosis**

Patient was diagnosed with Stage IIA Breast Cancer on 18/03/2014 after she had felt a lump in her breast. This information was obtained from the patient herself.

Formal diagnosis that was given to me from the oncologist: pT2N0M0 – Stage II Ductal Carcinoma, Oestrogen (+)

**Treatment Plan**

At first, after the diagnosis the patient had had six sessions of chemotherapy, a double mastectomy with immediate reconstruction, fifteen radiation sessions and a complete hysterectomy. She had completed her treatment and had been in full remission for six months. She had been put on a hormone suppressor for the next five years.

**FIRST CONSULTATION: 09/06/2015**

I saw her for the first session in a consulting room in the oncologist's private practise which met all the criteria for a therapeutic environment. It was comfortable, airy and private. The session was booked for an hour and a half. (Because she had requested for the therapeutic sessions, I wanted to have a full therapeutic session of an hour, therefore I needed the extra 30 minutes to explain the study and forms to be filled in).



After the formal introduction, I gave her a detailed explanation of this study without using complex terminology of what this study entailed and what would be expected of her as a participant. I explained that one of the aims of the study was for the oncology team, including the psychologist, to understand the psychological experiences and needs of the breast cancer patient better in order to provide a holistic service to enhance the quality of life of the breast cancer patient and her family. I gave her the demographic information and the consent forms to take home to read through on her own time. She could, if she wished, discuss it with her husband and it gave her more time to decide whether she wanted to participate in the study. I asked her, if she agreed, to bring the signed forms back with the next appointment. I explained the two questionnaires - the HADS Depression and Anxiety Scale and the Female Sexual Functioning Index – FSFI (see Chapter VI) and asked her to complete it when she had time and to return it back the next session.

I further explained to her that her participation was completely voluntary and that she could decide to stop her participation at any time without having to give an explanation or without any repercussions for her. I assured her of my commitment to the study and to her as my patient and gave her my cell number and encouraged her to phone me if anything worrying happened in between sessions that she would like to discuss with me. The patient said that she understood the information and that she would like to participate in the study. She said that she had asked her oncologist to see a psychologist and that she could benefit from therapeutic sessions. She said she felt that her husband would also benefit from a session but it wouldn't be so easy to convince him to come in for a session. He was aware of the fact that she was participating in a psychotherapeutic process. After the formalities and all the explanations we started with the session.

I asked the patient why she had requested to see a psychologist. She explained to me that everything regarding her diagnosis was very overwhelming, it had happened very quickly and she was so ill that she didn't have time to deal with anything. She said that she really had a need to talk about how she felt and what had happened to her. She wanted to talk to somebody that would understand her situation and give her some advice as to what to do. It was not just her who needed help but her young child and husband as well. I told her that we could

begin discussing any of her problems that she felt comfortable speaking about. She said she wanted to start with her current situation, specifically her hysterectomy, which had been done one week earlier. She said she was still in mild pain and discomfort and I should please excuse her if she seemed uncomfortable. She explained that her gynaecologist had suggested a full hysterectomy just after her breast cancer diagnosis the previous year, before the mastectomy or the chemotherapy. The rest of her oncology team had agreed with that because of her young age. She was thirty-two when diagnosed and her child was still a baby. She said that at that stage she was so overwhelmed by the cancer diagnosis and everything that had happened so fast that she had not been able to think about anything else or make a proper decision. She said her family was concerned about the hysterectomy because they felt that she could have another child. She felt satisfied with one child. Her husband did not necessarily share her vision. Her feeling was that, after her diagnosis, it was her decision to make. She is the mother of her only child and rather wanted him to grow up with her than have another child and not see either of them growing up. Although her husband was very sad in the beginning about the hysterectomy, he actually made peace with that fairly quickly. She said she had also decided to ask if it was possible to have a double mastectomy. The surgeon agreed and they had started with the breast reconstruction immediately after her mastectomy. She said she had taken the decision-making on herself from the beginning because she had realised that she would have to be the strong person for her child, her husband and her mother and grand-mother. She said she also decided immediately that she would survive the breast cancer and that she would go to any lengths to do so. Her husband had had a very big scare with her diagnosis because his mother died of breast cancer at a young age.

I asked her about her experience regarding the chemotherapy. She said: *“it literally feels like yesterday and the pictures in my head are still very vivid, I can even still feel and taste and smell the chemo.”* For her it had been very traumatic and scary. She first had chemotherapy before her double mastectomy. She had had the “Red Devil” first, for three times, (she used the term) and became extremely ill from that. She said she was completely unprepared for the side-effects, especially the nausea and the vomiting, for she had understood from

'other people' that nausea and vomiting were not such big problems anymore because of the anti-nausea medication, but in her case it was extremely vicious.

She explained that the picture in her head of the chemo room was so vivid she could still 'feel' it. She said that she had a biological reaction to the chemo immediately while still sitting there, her tongue felt "weird" and she had a vile taste in her mouth. She said the whole experience of her first chemo had been very overwhelming for her and yet she desperately felt she had to be strong for her whole family. During her first chemotherapy her mother accompanied her and waited in the waiting room sitting on a chair where her daughter could see her the whole time. She had not expected to be so sick immediately after the chemo and said she was completely unprepared for that. She had been nauseas and started vomiting a couple of hours after the chemo. She said the red colour and the smell of the chemo is still vivid from time to time. She vomited for days before she got better and none of the anti-nausea medication worked for her. Because she had gotten so violently ill she had not wanted her child to see her like that, and had tried as much as possible to keep him away from her when she was so ill. Her husband and mother had then taken over his care.

She said night time had been the worst for her because she was all alone and was thinking a lot about dying and her son growing up without her. She felt very vulnerable during that time and did not understand all of her emotions. She said she was very emotional during that time. She cried a lot and she worried constantly over her child and tried for him not see her in the state that she was in. The child was foremost in her mind. During the three days that she felt so ill, she constantly thought about death, was scared of dying the whole time, thinking "*what will become of the child if I die, he will not have a mother*". She said when she was so ill, nauseas and vomiting the whole time, she honestly wasn't so sure whether she would "make it". She often wondered if this was what dying felt like. She said that, despite of her crying and fear, her most prominent emotions were feelings of guilt. The feelings of guilt were especially towards her husband, who had already gone through the motions with his mother, and her little child who was missing out on her care. She had not been able to perform his daily care such as helping him get ready for pre-school in the mornings and taking and fetching him there. She said, apart from that, she was very tired. Her short term memory was,

and still is, very bad, the food had no taste at all and her left arm, where she had had intravenous chemo therapy, was hurting, It had been swollen and burnt. The pain was so bad that it woke her up some nights. She said she remembered that, the whole time that she got chemotherapy, especially the “Red Devil”; she made a conscious decision to focus on other things and not on the chemo. She said by the third day after the chemo, she could go back to her work and that she tried to be strong and in control and kept on telling herself she would make it. She said it was very important for her how people would look at her during the treatment and that they had to see how positive and strong she was and if she should die then, at least people would remember that she was a fighter and didn’t just sit back without even trying to fight. She said that the next three chemo sessions, which she called the “transparent” ones, also had severe side-effects on her namely:

- her throat was extremely sore and raw and she suffered from heartburn
- she had an elevated appetite and wanted to eat the whole day
- she slept poorly
- she was very tired
- she was swollen

I asked her about the chemo and her hair: and she replied that the loss of her hair did not worry her much personally, but she was very worried about her husband and child. She said her husband was very adamant that she should wear a wig when they went out in public. They immediately bought a wig. She had had long hair before and then decided to cut it shorter before the chemo began so that the difference would not be such a shock for her child. After the first chemo her hair started to fall out immediately and that was a shock to her. She and her husband shaved her hair at home and she let her child touch her head and tried to explain to him that her hair felt different because she was sick, but it would grow back again. She said he was fine with her bald head and she thinks it was because she involved him in the whole process of “shaving her head”. She also made a point to talk to her son about what was going on and tried to keep it at his age level.

We ended the session after an hour and a half and the patient said that she still had so much to talk about and that there were so many things that she wanted to ask about. She said she felt very excited about the sessions and already felt much

“lighter”. She had an urgent need to express her emotions and the hardships she had experienced during her breast cancer period. We scheduled a meeting for a week later and I said she could phone or message me if she was having a crisis.

## **SECOND CONSULTATION: 16/06/2015**

We had booked an hour session. The patient said that she felt better after the previous session. Merely the opportunity to have talked about the treatment and her experience of it made her feel lighter and less “abnormal”. It had been two weeks after the hysterectomy and she felt better than the previous session in terms of mobility and pain. She was still on sick leave and would only be going back to work in four weeks’ time.

I asked her about her emotions regarding her husband because that was one of the reasons she had asked her oncologist to be referred to a psychologist. She said the diagnosis of her breast cancer was a big shock to him because of his history with his own mother who had died of breast cancer at a relatively young age. She said she thought his reaction was so strong because he knew what lay ahead for her and she did not, because she had never before been confronted with breast cancer. She had no family history of breast cancer which is why the diagnosis came as such a shock to her and her family. She said her husband had experienced the idea of her hair falling out very negatively and preferred her with a wig. They had only been married for a couple of years and she felt that he had not tried to understand or support her enough during her illness and she felt abandoned by him. She felt that her perception of support and his perception of support were completely different and felt that her mother had been more hands-on and supportive during the whole cancer process than he had been. She felt that the whole cancer experience was embarrassing and shameful to him and it made her feel more vulnerable and alone. She said they had had a lot of conflict during her cancer treatment especially when she felt irritable or miserable. Although her cancer treatment was over, she still felt that their relationship was not at a good place. She said she felt a lot of resentment towards him. He didn’t make an effort to understand her emotions during her cancer phase and felt that the cancer stood between them. She said that now, when they fight about something, he would refer to the time of her cancer treatment saying that she had been

irritable and abrupt or blunt. He didn't speak easily, especially about emotional matters, while she on the other hand wanted to talk about how she felt and her emotional needs. She said that from the beginning, when she heard that she had cancer, she talked about it, which was her way of dealing with things. He did not agree with her way of dealing with her illness. She said he wanted her to keep it more private, which confirmed her point that he was ashamed of her cancer and looks. She said because of the conflict in their marriage and her emotions regarding her cancer, she had asked her doctor to refer her to a psychologist. She said she felt depressed about her losses and because of her marital problems. It would therefore be good to begin our consultations by discussing the problems in their marriage. I asked her if there is, or was, any change in her mood and she said she had been feeling very depressed and emotional for a while now. I decided to evaluate her for a major depression using the criteria of the DSM 5. She presented with most of the symptoms, including a change of her sleeping and eating patterns, lower energy levels, lower drive, and incapacitation of concentration, attention and memory, having more negative and irrational thoughts than positive thoughts and a low libido. I explained to her that she had symptoms of depression and that we could treat the condition with either psychotherapy alone or in combination with an anti-depressant. She said that she wanted to give the therapy a chance first before we go for the option of medication.

She also asked if she could bring her husband to the next session and we agreed on a joint therapy session and possible couple's therapy.

I asked her about her background. She said she grew up in a fairly stable household with strong willed women and that she learned from a young age to fend for herself, to be strong and to handle stress effectively. She perceived herself as somebody who could handle stress in a positive manner and did not tend to fall victim to negative situations. She said she had had a strong family support system throughout her life and especially during her cancer and cancer treatment. She had never experienced depression or anxiety before the cancer, or had had any treatment for such conditions, but she was very worried and troubled by her emotions and relationship with her husband.

As with the first session, this session led to much emotional catharsis. The patient stated that she really needed to talk about how she had felt since her breast cancer diagnosis and throughout her treatment. This was especially the case after the treatment had been successful and she was in remission. She said she thought that once it was all over she expected to (automatically) feel better, but it was not the case.

We ended the session after an hour with a date for the next appointment, which was a week from that day.

### **THIRD CONSULTATION: 23/06/15**

The patient came to the appointment alone, saying her husband didn't want to come to the session with her. She was very discouraged and disappointed. She felt that her husband would understand her illness and her current emotions better if he understood the cancer and cancer treatment fully. She felt that maybe if he heard the information from a professional person he would understand her and her circumstances better and she said she would again try to bring him next time.

I gave her reassurance that it was sometimes difficult for a partner to participate in therapy because of the stigma that it holds for some people to visit a psychologist. It was similar to showing some kind of "weakness". She should continue talking to him about how she would appreciate it if he came with her to a session. I also explain to her that if she asked him to come with her for a session, she should explain to him that it would be for him to understand her cancer and herself better and that they would both benefit from a joint session. In other words, she had to explain to him that the session would be about her and her problems, and not because there was something "wrong" with him. I also explained to her that in my experience as a therapist, working with cancer, I often found that a partner could feel that they should have therapy because they are "at fault". Maybe if he understood that the session was about her and the cancer, he might feel less threatened. She said that made more sense to her and that she would try to convince him using this angle.

She said that even if he was not there she wanted to talk about her feelings regarding their marriage. She felt that currently she stressed a lot because of the

relationship with her husband and was scared that the amount of stress that she felt would affect her body and disadvantage her in terms of the cancer. She said that currently, because of the hysterectomy two weeks prior, they had to abstain from sexual intercourse, which was quite difficult for him.

I asked her about their sexual functioning. She said that they had always had a very good sex life and were sexually very compatible. She thought he was presently all right with her body but because of the breast reconstruction surgery, her breasts were still sensitive to touch. They had continued their sexual functioning after the breast surgery until the hysterectomy. They were still young and were sexually very active as a couple. She was very scared in the beginning when she realised that her body would look different, that her husband might be repulsed by her body and therefore had decided immediately that she would have reconstruction surgery as soon as it was possible. She said she didn't want him to see her without breasts and that it was very important to her how her husband saw her as a woman. She said: "*I will go to any length to restore my body image*". She asked if I could tell her about her hormone medication that she would have to drink for the next five years, because she understood that the medication would also affect her sex life.

I asked her if her doctor had explained the side-effects of the hormone treatment to her, and she said that the doctor had explained it to her regarding menopause, but she felt she needed more time and information about it. She wondered what it would do to her body since it was something unfamiliar to her.

### **Therapeutic input**

Firstly I explained to her that early or premature menopause could be shocking for a young women and it was important to understand the 'mechanics' of premature menopause in order for her to adapt to her new situation. I explained that premature menopause happened very abruptly, whereas with natural menopause, the body and mind had time to adapt to the changes because they happened over a period of time. To accept something as 'unnatural' as premature menopause, lay in the conscious mind where you could decide to make peace with, and accept it through the learning of new skills of adaptation. The processes of making peace and acceptance have to do with realising and understanding your losses and



working through an active grieving process too. The losses that we discussed were; the lack of oestrogen and the influences of this on the body and mind; the manner of sexual reaction of her body before menopause and that the fact that she would “lose” at least 20 years of having a young body which would have had enough oestrogen. I emphasised that the hormone therapy, even with all the negative side-effects, would help reduce the risk of the cancer returning, and is usually used for at least five years as her doctor had explained to her.

Secondly I explained what menopause involved in terms of symptoms and the impact on her body and her sexuality. I explained that everybody doesn't have all the symptoms or have them to the same degree but is helpful information for at least she would know what to expect. I explained about the hot flushes, night sweats, sleeping problems (insomnia), possible weight gain and slowed metabolism, possible thinning hair and dry skin. Menopause could also influence her mood, causing mood swings, irritability and even depression and a decreased libido (which means a lessened sex drive). There was also a risk of losing bone mass or density which could lead to osteoporosis. We discussed how to deal with the biological symptoms of menopause, such as gathering information about menopause by reading, being physically active and including activities such as walking or other types of exercise such as yoga. This she could do when her body was well again and she had permission from her doctor to exercise. She could learn techniques to handle her mood, especially depression. We agreed to make it a goal for a future session to discuss depression and for her to discuss symptoms such as hot flushes with her doctor.

We also discussed what she could expect of her and her partner's sexual functioning after the period of absence due to the hysterectomy. I described the importance of intimacy when the sexual act was not possible (like then) and that resuming one's sexual activities were much easier when there were still other forms of bodily contact like holding hands, kissing, etc. I explained that a decreased libido meant that she would not always feel in the mood for sex biologically, but that she, by way of her mind, could think and talk herself into sex and still enjoy the act even if she was not automatically aroused from the beginning. I also said she should discuss with her husband and explain to him her lower libido so that he could understand that it had nothing to do with him, but that

it was rather a biological side-effect of her cancer treatment. She should inform him that they could work around that. It could be a learning curve for her to find out and experience what would work for her sexually from then forward. It might be different from before the cancer and the menopause. For instance, foreplay might take longer because she might need more time to get aroused and that she needed to use liberal quantities of lubrication (because of vaginal dryness) to avoid painful and uncomfortable sex. This was a good time to try new sexual styles and positions that could work in their unique situation, but talking and including her husband, was the most important part of this new sexual journey.

The session came to an end and the patient said that she really wanted her husband to come with her to the next session so that I could explain to him the changes in her body and sexual functioning in the future. She said she felt very positive about the information that she had received and felt much lighter about her sexuality than before she had come in that day. We made an appointment for a week from then.

#### **FOURTH CONSULTATION: 01/07/2015**

My patient's husband had accompanied her for the session on her request to explain her emotional reactions regarding the breast cancer to him. He did not sign a consent form, but I explained the study to him and especially the psychotherapeutic element of the study. He was well informed about the study before the process began. I introduced myself and thanked him for joining us in this session. I started by asking him if he had any questions for me about the course or content of the session or anything else that had to do with his wife and their current situation. He said that he had no specific questions and that he was there to listen to what I had to say regarding his wife.

I then asked my patient if there was anything that she wanted me to discuss with her husband and if she felt comfortable with me discussing her situation with him. She consented, and said that she would like me to explain to him what I had explained to her during the previous session regarding all the changes in her body especially due to the menopause and what to expect sexually from her in the future.

I started with the menopausal symptoms by explaining the biological side-effects first. The hot flushes (she said then that the hot flushes were very bad, especially at night), sleeping problems (insomnia), possible weight gain and slowed metabolism and a decreased libido, which meant a diminished sex drive. I also explained that her body would react in a different way because of the cancer treatment, the hysterectomy and the hormone medication that she would drink for the next five years as well as the chemically induced menopause. I explained to him that she would have to use 'aids' during sex, such as a lubricant, because her body would not produce its own vaginal lubrication anymore and that they would have to try different (new) things and ways to have a satisfying sex life again. By means of intervention, they could start by talking more about sex and their sexual desires and needs and what they liked and disliked. They could also try new positions or different places, (sex outside the bedroom), to improve their sex life. I explained that menopause is a natural occurrence for older women but because of the cancer, his wife would now prematurely develop menopausal symptoms and that she would not have the longer period of time that comes with natural menopause to get used to the symptoms and changes. She would need his support and understanding of this premature process to make peace with it and accept her body and still be a good sex partner to him. Menopause didn't mean that they would not have a good and regular sex life, but there would be differences and changes and by accepting that they would be able to develop new skills for a new sexual status quo. He had to be aware of her lower libido and understand that the fact that she did not have a natural desire for sex didn't mean that he was at fault, but that it was due to a biological reaction. In order to get her stimulated might take "harder work" from his side, especially concerning foreplay which might take longer than previously.

We then went on to the emotional effects and I explained what he could expect of her in terms of her emotions and moods. I also clarified some of her previous emotions such as her depressive moods and irritability while she had had chemo and explained the effect that chemotherapy could have on a person's mood. I emphasised, that it had to do with the chemicals and not the person and he should not take it personally. I explained to both of them the process of accepting and adapting to this 'after-breast cancer' life by understanding that they as individuals

and as a couple would never be the same as before the cancer experience and that they should be able to make peace with a new way of living. This they could achieve through an active grieving process and especially allowing themselves to go through their bad and negative emotions, talking to each other about their emotions and making plans together on how to develop new ways to adapt in the future. It was important for them to look at themselves as a team working towards an end goal, and not just as having an individual journey.

We talked about how he could support her when she felt down or anxious and the patient told him that just by understanding her and listening to her when she talked about how she felt, would make her feel accepted and supported by him. She also asked him to talk to her about how he felt about her cancer and their sex life. Communication was very important to her. She told him that she was scared that he might reject her, especially sexually. However he said that he felt the same about her as before the cancer and that he was still strongly attracted to her sexually and that he now understood the adjustments that they had to make. He had never seen it in this light and her emotional reactions made more sense to him now. The patient said to him that hearing him saying the above, already made her feel more accepted by him.

I asked if he had any more questions about the above and he said he understood things better now and he would make an effort to accommodate the changes. I reminded both of them of the chronicity of the situation and that it was a lifelong process of making peace, adapting and learning new skills for the future. They should take into consideration that it would take time and that it remained a team effort.

Before we ended the session, the patient said that she had had good news from the gynaecologist and that everything was fine regarding the hysterectomy. In seven days she had to go back to the oncologist for her sixth month's tests but although she was a bit nervous, she was also feeling positive about the results.

We ended the session on a good note, where both of them felt more positive and informed than before the session. We made another appointment for one month from then, for an individual session.

Therapeutic note: This was both a psycho-education session in terms of side-effects of the chemo therapy, hormonal treatment and menopause and especially the effect on their sex life. This session also served as an opportunity for the patient and her husband to have an emotional catharsis because they had both shared their emotions with each other and experienced the benefits of communicating their feelings. They both understood the importance of putting certain experiences and emotions in the framework of the breast cancer and cancer treatment.

#### **FIFTH CONSULTATION: 02/08/2015**

The patient looked much more relaxed than the previous sessions. She immediately started giving feedback regarding the mutual session with her husband the previous time. She said that in spite of the fact that her husband was apprehensive about their joint session, he had experienced the session rather positive and that after the session she could see a change in his behaviour. I had also experienced him as very unapproachable and curt in the beginning of the session. She said that they talked more to each other and he was making an effort to spend more time at home with her. She said she felt more accepted and understood by her husband, although she knew that there was still a long road ahead of them to grow and adapt. She felt for the first time that he was on board. The patient had very good insight into herself, her condition and her relationship with her husband. She was also very committed and positive about the therapeutic process.

She had gone back to work for the first time six weeks after the hysterectomy and said that she was actually coping very well. She said working was very important to her and even during her chemotherapy she had worked the whole time and had always tried to schedule her chemotherapy on a Friday, so that she didn't need to take off from work. She said she found her colleagues very supportive and good to her. Before she had gone back to work she had been scared that her energy and concentration would fail her, but she could see a difference in her energy levels and although her concentration and memory was not up to her usual standard, she could work around it.



## **Therapeutic input**

I explained to her that the lack of energy, concentration and memory, which could still be side-effects of the chemo, would take a while before it cleared and that she had to give herself some time to recuperate from the breast cancer ordeal. She could make use of alternatives to handle these problems for instance, making little notes to remember things, or to take more breaks to help with her concentration and to rest more and reserve her energy through prioritising. I reinforced the importance for her to understand the cancer related symptoms and that most symptoms usually got better and disappeared over time. We talked about accepting the fact that there would be a difference between how she had been before the cancer and her current functioning now, after the treatment and that it took a process (e.g. working through her emotions and learning new stress handling- and coping skills) and some time to adapt to a “new” post-breast cancer status quo. The patient said the fact that she understood her level of functioning better and that it was only temporary, made it seem less threatening and scary.

The patient said she was very wary not to stress too much, as she knew stress was not good for her or the cancer and that she would like to learn some skills so as not to worry so much. I explained to her different mechanisms of handling stress in terms of your mind/thoughts. There were cognitive processes and behaviour (things wat you do). I would give her examples of how to relax:

### **STRESS HANDLING MECHANISMS**

Firstly I explained basic breathing exercises to her by saying that one of the first things when stressed or to prevent stress is to concentrate on relaxing the whole body and to do relaxing breathing:

- Firstly I explained how to do it. You can sit or stand, but make sure to soften the body a little before you begin. Make sure your hands are relaxed (open) and drop your shoulders and let your jaw relax. Take a slow breath in through your nose and count to four, keep your shoulders down and allow your stomach to expand as you breathe in
  - hold your breath for one or two counts
  - Now release your breath slowly and smoothly as you count to four

- Wait a few seconds before taking another breath and repeat the exercise for a couple of minutes.
- Secondly I explained a quick way of relaxing her whole body:
  - stand up straight and tall and let your arms hang naturally
  - breathe in slowly through your nose whilst tensing all your muscles
  - hunch your shoulders, make tight fists with your hands, tense your stomach and clench your buttocks, push yourself up onto tiptoe position and hold and count slowly to five
  - slowly breathe out through your nose while relaxing and return to your original standing position
  - repeat the above 3 to 5 times or as time and circumstances allow

These are relatively easy breathing and muscle exercises that she could do any place or time and not just wait for a situation which is stressful. She should concentrate during the day to do proper breathing.

- Thirdly I explained that it is important to exercise after your doctor had given you permission to exercise again, such as walking or yoga which is a very good and healthy way to get the extra adrenaline out of your body and give your body more oxygen and time to think things through.
- Fourthly I explained that she should take control of her thoughts through mind control: This entailed the process of focusing away from negative and disturbing thoughts by identifying and accepting the negative or irrational thoughts without judging them or fighting them and then focussing on other, more rational and positive thoughts. I also explained the importance of focusing on the here and now, such as what was happening around you at that moment, what you were experiencing and what you could do to feel better, such as phoning a friend, making a cup of tea, doing something in or around the house, or just walking around. This would help her to focus away from the disturbing thought(s).

I summarised the session by asking her to think about all the new information that she had received and to begin implementing them one small step at a time. She

should give me feedback during the following session. The patient said that she felt excited about the new skills. It made sense to her and she could not wait to start doing it. We ended the session after one hour and ten minutes with a follow up session planned for three months from then. The patient said that she felt much better and would like some time to implement the above mentioned skills.

#### **Sixth consultation: 10/11/2015**

During this feedback session that had been planned three months before, the patient seemed in good spirits and looked much more relaxed during this session. She seemed fit and healthy. She reported back that since the session with her husband, they were functioning much better as a couple. They talked more, did more things together and her husband was more attentive to her than previously. Even sexually she could see a huge difference. She said what made her excited was that it had been three months after the previous session and her husband was still committed to his “new” behaviour. She said the mere fact that her husband was more understanding and supportive, made her feel much better in general.

She said that her chemo-related symptoms, especially the tiredness and concentration, were also less and that she could see that in her functioning at work. She said that they were extremely busy at work and that she could keep up one hundred percent. She said this made her feel worthy as a “worker” again. Keeping up with her child made her very tired and she had to manage her time and activities with him very carefully.

#### **Therapeutic input**

I just emphasized again the principle that who she had been as a person, wife and mother before the breast cancer and cancer treatment, did not exist anymore and that there was a “new” person, wife and mother this side of cancer. This was not necessarily negative, just different, and required new skills and adaptation. She said that every time something happened that was different from before the cancer, she remembered this principle and consciously applied it by having new thoughts or actions and tried to accept and make peace with it. We talked about practical ways of playing with her child without getting too tired, for example,



instead of running around and playing with a ball she and he could participate more in passive games like colouring in, playing hide-and-seek in the house or reading or watching TV together. It was very important for her to be involved in her child's life and by altering her actions and time with him in a more suitable way for her, would prevent her from feeling guilty of not spending enough and quality time with him. She said that during the time that she had had her treatment and had been very ill because of the chemotherapy, she could see a difference in his behaviour and that his teacher had also commented on his changed behaviour. She said it was as if he had regressed during that time, especially when she had been in hospital. She still experienced feelings of guilt over that. I gave her time to talk about her guilt feelings and guided her to put her feelings into perspective of her illness and commented that she, in spite of her condition, was still very involved in his life during that period of time.

Although her breast reconstruction surgeries were finished, something had happened and she had to undergo a procedure the following month. This meant a two day stay in hospital. She said she was not scared, but felt that she had had enough of hospitals and wished it was over. She said the only thing that really stressed her regarding her stay in hospital, was her son who got tense when she went to hospital and she asked me how to approach him.

### **My input**

She had to stay as close to the truth as possible and explain to him that she was going to the hospital for two days, but not because she was sick again, but to "fix" her breast. He knew about the breasts and the operations because "they got sick". She could explain to him that he would stay with his father and that he would still go to school. Everything would go on as usual and he could visit her in hospital. On a practical side, she could prepare his favourite meal and put it in the freezer and he could eat it when she was in hospital, and he would "think" of his Mommy still making his favourite meal even if she was in hospital.

She said another aspect that made her anxious was all the tests that she would have to go through again in two months from then. She said she was scared but would definitely use the relaxation breathing and exercises. We talked about the chronicity of breast cancer and that although she was in remission, she would still

have to take the hormone medication for five years. She would need to go for lifelong follow ups and tests which would make her anxious and scared. This was also a normal reaction to the situation. It was important to accept this anxiousness as normal and work with it instead of against it by talking about how she felt, focusing away from destructive thoughts and to use relaxing methods to gain control.

I have found as a therapist that the mere fact of normalizing emotions and thoughts for a patient, may take away a lot of tension and anxiety and make the person feel more in control of herself and her thoughts and emotions. We ended the session by scheduling a session three months from then.

### **SEVENTH CONSULTATION: 10/02/2016**

The patient looked very well and she said that she felt good and healthy. First she gave feedback of the previous three months that I had not seen her, saying that she had gone for her full blood tests and the other cancer tests and scans and had seen the oncologist the previous month. She said she had been anxious, but kept it in mind that it was “normal” and that she could manage it and that it was not necessary to fight against it. She said that everything was hundred percent normal and that she had been in remission at that time for thirteen months. She said that she felt extremely happy and good about her health and that she made a point of not thinking about the cancer anymore. She said that her and her husband’s relationship was still good and at a much better functioning level than before and that they still used the therapeutic guidelines from our mutual therapy session. She said even the sexual functioning, considering her hormonal therapy, was good and enjoyable.

Her functioning at work was good; she was enjoying her work again and handled her work-related stress well. She said that, in general, her health and functioning was at a high level and that she enjoyed life to the full again. I asked about her depression symptoms and she said that she felt less depressed and anxious and that she could feel that because of the therapy her overall level of functioning was higher than before. It was only when she thought or talked about her child that she felt some degree of depression. She asked whether we could talk about her child again, for he was still not at his previous level of functioning and it worried her.

She talked about her feelings regarding her child saying she was still scared that the cancer might return and that he, being an only child, would grow up without his mother and other siblings. She said she had a lot of sad feelings and anxiousness when she thought of him growing up without her. I gave her time to express her emotions, especially the fear and guilt feelings regarding her child. I also explained how important it was for her to allow herself to go through the motions and express these feelings, for it was normal to feel that way. We concentrated on how, after accepting and accommodating the negative and anxious thoughts, she could focus on the reality of their relationship, and participate in present activities. She said she felt better for talking about her emotions concerning her child. She was feeling guilty and ashamed of herself, because she was actually cancer free but yet she was stressing about dying from cancer. She didn't feel like sharing this with anybody else. She said that she felt that this was one of the biggest "perks" of going to therapy. You could speak about everything and anything which you couldn't speak about to anybody else without being judged or being frowned upon.

She said she had received the "green light" from her oncologist and had started to exercise again. She said it made a huge difference in how she felt and looked. She said she had gained a couple of extra pounds during her cancer treatment, but could already see the difference from the exercising. She said that being able to exercise again made her also feel more social and "in" with the "normal" crowd. She said she felt really "normal" again, being able to do "normal" things. She asked whether it was possible to see me every three or sixth months for a therapeutic session, for she found that by talking about her emotions and receiving the appropriate feedback, and being taught new mechanisms and skills, improved her functioning and made her feel in control of her own life. I agreed to such an arrangement saying that it was a good way of maintaining her emotional health, but for the sake of the study we should make one final session to conclude our therapy, also three months from then. From there on we could participate in the usual follow up sessions if she still wanted to.

#### **Eighth and final consultation: 15/05/2016**

We made this appointment to conclude the therapeutic process. This session was booked and lasted for one hour. I let her to talk freely and lead the session. The

patient looked very good and said that apart from a couple of complaints she actually felt physically well but needed to talk to me about emotions and certain concerns. She asked again if it would be possible for her to keep on scheduling appointments with me every couple of months for she felt that seeing me made her feel comfortable and that we already had a therapeutic relationship. She said that for her family and friends her cancer experience was now something of the past, but she felt that she needed, from time to time, to talk about it with somebody from the outside. She felt that her family and friends would not understand this need to talk about the cancer after everything because it was over and she was cancer-free. She also said that she could understand that “outside people” could not understand the change from being a cancer patient to a “normal” person.

The first issue that she wanted to discuss was her short-term memory. She said that it was still a serious problem for her. She could not remember things and it affected her marriage and her work. She said her husband complained about it all the time, saying that when he asked her to do things for him, she didn't do it although she said she would. She said the lack of memory often instigates conflict between them and felt that he did not understand her problem with her memory. She said that she was very worried about her work for she worked with figures and had a responsible job and was scared that she would make mistakes. She said that, never in her past, had she had problems with her work performance and did not want to jeopardise her job, for they were dependant on her salary.

### **Therapeutic input**

I reminded her about memory loss as a side-effect of chemotherapy and that it could be a long term effect which could impact her negatively in certain areas of her functioning. The most important thing for her to do was to understand and acknowledge it as a cancer treatment related problem and to accept and make peace with it. It was not necessary to panic about it as it was “normal” in her situation. Her immediate reaction to this was pure relief, saying that although she could remember us talking about chemo and memory, she was still unsure why she had such a problem with it and it really scared her because the cancer treatment had ended so long ago. She said as long as she knew that there was not something wrong with her, she would be able to cope and deal with it. I

reminded her to be conscious about her thoughts, identify any irrational thoughts and replace them with rational and “true” thoughts. On the practical and behavioural side, she could make notes (especially at work) and write all the important things in her diary to check from time to time to make sure everything was done. By doing something about the problem would make her feel more in control and lessen the probability of her making unnecessary mistakes at work. In her everyday life, as with her interactions with her husband, she could also make notes of what he had said and asked her to do and make a daily to do list in terms of the household. She shouldn't feel embarrassed about it; it was part of where she was in her “post-cancer” life now.

The next topic that she wanted to talk about was her weight and lack of hormones. She said that although she had not gained weight she weighed more than before the cancer but had made peace with it. She said that she exercised regularly and was conscious about what she ate. She would like to make another appointment to talk about her self-image and sexual self-image. She said she understood the impact of the menopause on her sex life and emotions but just wanted to check with me again regarding it. I restated the symptoms of menopause again and what to do when her libido was low, especially her thoughts regarding her libido and plans to enhance a low libido (e.g. think about sex more often, buy books about sex and talk about it more with her husband) and she could organise date nights with her husband and try different sex scenario's (e.g. engaging in sex outside the bedroom). I reminded her that everything took time and that she should cut herself some slack and reward herself when she got something right or when a side-effect got better and she should enjoy her better relationship with her husband and interactions with her child. She said that she could see that her child's functioning was also better and that he didn't ask about her going to hospital as often as during the cancer treatment. She felt very positive regarding the progress of her child and their functioning as a family.

I asked her to summarise her experience of the therapeutic process so far. She said there were so many advantages that she didn't know where to start, but the mere fact that she could talk to me about anything, even her sex life and deepest fears and thoughts, made her feel better and more in control of her life again. She said what made a big difference to her was that she felt so “normal” again after

talking about all her feelings and thoughts and experiences, understanding that other woman in her situation also felt that way and that she was not the only one. She said she thought it was the receiving of information regarding all the unfamiliar things that was happening to her that made her more relaxed and had put her mind to rest about her concerns regarding for instance her tiredness and lack of memory and menopause. She said when she started with therapy she was so depressed and anxious all the time not knowing what was happening to her, but felt that she understood her own emotions and reactions much better now which made her feel better, saying: *“I feel more in control of my own body and my own thoughts and feel just all together lighter”*. She said she felt very strongly about therapy and cancer, because it helped her and her husband and child a lot during “their” cancer journey. We ended the session after an hour with the patient making an appointment for a next session to work on her self-image.