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List of Abbreviations

ACT	Acceptance and commitment therapy
ANCOVA	Analysis of covariance
ANOVA	Analysis of variance
APA	American Psychological Association
APIM	Actor-Partner Interdependence Model
BDI	Beck Depression Inventory
B-IPQ	Brief Illness Perception Questionnaire
CBT	Cognitive behavioural therapy
cSCCHN	Cutaneous squamous cell carcinoma of the head and neck
CSM	Common sense model of self-regulation
DSM	Diagnostic and Statistical Manual of Mental Disorders
EBV	Epstein-Barr virus
FACT-H&N	Functional Assessment of Cancer Therapy-Head and Neck
GHQ-12	12-Item General Health Questionnaire
HNC	Head and neck cancer
HPV	Human papillomavirus
HRQL	Health-related quality of life
MBSR	Mindfulness-based stress reduction
MOH	Ministry of Health
NCCN	National Comprehensive Cancer Network
NCI	National Cancer Institute
PSS-SR	PTSD Symptom Scale Self-Report Version
PTSD	Post-traumatic stress disorder
RCT	Randomised controlled trial

Awards and Publications

Publications

- Broadbent, E. & Richardson, A. (2014). Interventions to change illness perceptions. In P. Henningsen & W. Rief (Eds.) *Psychosomatik und Verhaltensmedizin*. Stuttgart: Schattauer Publishing.
- Richardson, A., Broadbent, E., & Morton, R. P. (2013). Coping mechanisms in patients with head and neck cancer. *International Journal of Cancer Research and Prevention*, 6, 47-87.
- Richardson, A. E., Morton, R., & Broadbent, E. (2015). Caregivers' illness perceptions contribute to quality of life in head and neck cancer patients at diagnosis. *Journal of Psychosocial Oncology*, 33, 414-432. doi: 10.1080/07347332.2015.1046011
- Richardson, A. E., Morton, R., & Broadbent, E. (2015). Psychological support needs of patients with head and neck cancer and their caregivers: a qualitative study. *Psychology and Health*, 30, 1288-1305. doi: 10.1080/08870446.2015.1045512
- Richardson, A. E., Morton, R. P., & Broadbent, E. (2016). Changes over time in head and neck cancer patients' and caregivers' illness perceptions and relationships with quality of life. *Psychology and Health*, 31, 1203-1219. doi: 10.1080/08870446.2016.1203686
- Richardson, A. E., Morton, R. P., & Broadbent, E. (2016). Coping strategies predict post-traumatic stress in patients with head and neck cancer. *European Archives of Otorhinolaryngology*, 273, 3385-3391. doi: 10.1007/s00405-016-3960-2
- Richardson, A. E., Morton, R. P., & Broadbent, E. (2016). Illness perceptions and coping predict post-traumatic stress in caregivers of patients with head and neck cancer. *Supportive Care in Cancer*, 24, 4443-4450. doi: 10.1007/s00520-016-3285-0
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Elizabeth Broadbent	Study conception and design, review of data analysis and assistance with interpretation of results, proof-reading of manuscript, approval of submission

Certification by Co-Authors

The undersigned hereby certify that:

- ❖ the above statement correctly reflects the nature and extent of the PhD candidate's contribution to this work, and the nature of the contribution of each of the co-authors; and
- ❖ that the candidate wrote all or the majority of the text.

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Elizabeth Broadbent		18 August 2016

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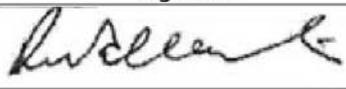
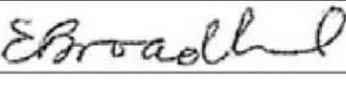
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Chapter 6. Illness Perceptions, Coping, and Post-Traumatic Stress among Caregivers	
Richardson, A. E., Morton, R. P., & Broadbent, E. A. (2016). Illness perceptions and coping predict post-traumatic stress in caregivers of patients with head and neck cancer. <i>Supportive Care in Cancer</i> , 24, 4443-4450. doi: 10.1007/s00520-016-3285-0	
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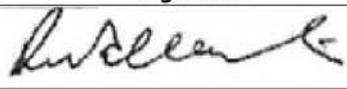
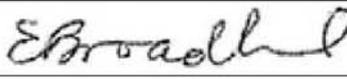
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Chapter 7. Psychological Support Needs of Patients and their Caregivers

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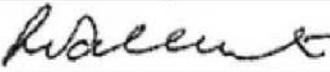
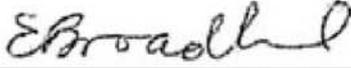
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Chapter 9. A Self-Regulatory Intervention for Patients with Head and Neck Cancer

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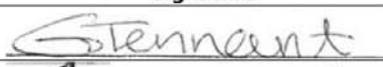
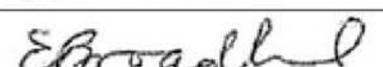
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Randall Morton	Provision of expertise in head and neck cancer, proof-reading of manuscript
Elizabeth Broadbent	Study conception and design, review of data analysis and assistance with interpretation of results, proof-reading of manuscript, approval of submission

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Chapter 1. Overview

Cancer is well-recognised as a challenging disease that negatively affects physical and psychological wellbeing. A high prevalence of psychological distress has been documented among patients from diagnosis through to treatment, as well as in the years thereafter (Burgess et al., 2005; Derogatis et al., 1983). Approximately 40% of patients with cancer report experiencing distress at any given time point (Carlson & Bultz, 2003). This has led to the recommendation that distress be recognised as a core indicator of patient health, along with vital signs of temperature, respiration, heart rate, blood pressure, and pain (Bultz & Carlson, 2005). Fortunately, increasing efforts have been made to identify patients with cancer who are at risk of experiencing high distress following diagnosis (Carlson, Waller, & Mitchell, 2012), and a number of psychological interventions that are effective at reducing distress and improving overall wellbeing have been developed (Faller et al., 2013).

Head and neck cancer (HNC) encompasses cancers that arise in the mucosa of the head and neck (including the oral cavity, lips, pharynx, larynx, and oesophagus), and cancers in the nasal cavity, paranasal sinuses, and salivary glands (Argiris, Karamouzis, Raben, & Ferris, 2008). As a consequence, HNC often compromises complex anatomy that is essential for a number of basic functions, including breathing, eating and drinking, and communication. The disease and its treatment can also result in severe disfigurement in the head and neck region (Hagedoorn & Molleman, 2006), considerable pain (Chaplin & Morton, 1999), and mortality (Carvalho, Nishimoto, Califano, & Kowalski, 2005). The challenges presented by HNC suggest that it is one of the most distressing forms of cancer to experience. A number of calls have been made for more research in this patient group (e.g. Howren, Christensen, Karnell, & Funk, 2013), given limited information available regarding factors that can explain variation in patient recovery (Humphris & Ozakinci, 2006), and whether psychological interventions can be of benefit for patients and their families (Semple et al., 2013).

While predictors of psychological outcomes and psychological interventions have been studied extensively in patients with a broad range of cancer diagnoses (Newell, Sanson-Fisher, & Savolainen, 2002), this is not the case for patients with HNC. Identifying factors that may contribute to enhanced patient psychological wellbeing and health-related quality of life (HRQL) is of great importance considering that these patients experience higher rates of depression and anxiety than patients with any other cancer type (Massie, 2004), as well as low levels of HRQL following their treatment (Ronis, Duffy, Fowler, Khan, & Terrell, 2008). Informal caregivers of patients with HNC (including spouses,

family members, and close friends of patients) are also strongly affected by a patient's diagnosis, reporting higher levels of anxiety, fear of cancer recurrence, and post-traumatic stress than patients (Longacre, Ridge, Burtness, Galloway, & Fang, 2012; Posluszny et al., 2015), in addition to significant strain and burden (Baghi et al., 2007). Nevertheless, psychological factors that place HNC caregivers at risk of poor outcomes are yet to be investigated, and interventions that might help to improve wellbeing in this group have not been identified.

The aims of this thesis are two-fold. The first aim is to identify whether illness perceptions and coping at diagnosis can predict variation in psychological outcomes among patients with HNC and their caregivers, both cross-sectionally and longitudinally. The second aim is to determine whether the modification of illness perceptions and coping using a brief psychological intervention can improve HNC patient HRQL, as well as patient and caregiver psychological wellbeing.

In the following chapters, evidence highlighting the particularly distressing nature of HNC is provided, a rationale for the investigation of patient and caregiver illness perceptions and coping is developed, and the absence of evidence-based psychological interventions to improve psychological responses to HNC is emphasised. The results of two empirical studies designed to address the aims of this thesis are presented, including an observational prospective study (from which five manuscripts have been published) and a pilot randomised controlled trial (from which a manuscript is currently in submission). A brief overview of the thesis structure is summarised below.

In order to give context for the proposed research, Chapter 2 outlines why HNC is so difficult for patients to contend with by documenting common symptoms of the disease, types of treatment and their associated side effects, and the enduring impact of symptoms and treatment side effects on patient HRQL. The high rates of psychological distress (particularly depression and anxiety) evident from diagnosis through to several years post-treatment among patients and their caregivers are documented. Furthermore, the capacity of illness perceptions and coping to predict variation in HNC patient and caregiver wellbeing is explored. The number of studies investigating these variables among individuals managing HNC is low, particularly with respect to caregiver illness perceptions, and how these relate to both patient and caregiver psychological health. However, evidence from research in those managing other chronic illnesses is used to show that illness perceptions and coping might also be important predictors of recovery for this group.

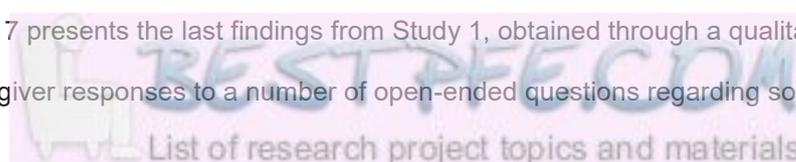
Initial support for the notion that patient and caregiver illness perceptions are related to outcomes in patients with HNC is provided in Chapter 3, where the first findings of Study 1 are presented. Study 1 examined baseline variables that might predict HNC patient HRQL, as well as patient and caregiver psychological wellbeing, at 6 months post-diagnosis. The cross-sectional results of this study describe relationships between patient and caregiver illness perceptions, and how these interact to influence different aspects of patient HRQL at diagnosis (Richardson, Morton, & Broadbent, 2015a).

Limitations associated with cross-sectional findings are addressed in Chapter 4, which provides the results from a longitudinal analysis of Study 1, examining whether patient and caregiver illness perceptions at HNC diagnosis predict patient HRQL 6 months later (Richardson, Morton, & Broadbent, 2016a). In particular, the role of discrepancy between patient and caregiver illness perceptions is explored using the Actor-Partner Interdependence Model (APIM; Cook & Kenny, 2005). This model is increasingly used to investigate dyadic relationships, which remain under-researched, not only in the context of HNC but also cancer more generally (Shin et al., 2013).

After noting the significance of patient and caregiver illness perceptions for patient HRQL, the focus of Chapter 5 turns to the role of patient coping strategies. The publication documents the results of correlation and regression analyses which were employed to examine associations between coping strategies at diagnosis and patient outcomes at 6 month follow-up (Richardson, Morton, & Broadbent, 2016b). Specifically, the contribution of avoidant coping to subsequent post-traumatic stress disorder (PTSD) symptoms is considered, in light of limited research that has investigated predictors of this outcome among patients with HNC.

In Chapter 6, attention is turned to caregivers of patients with HNC, with a publication that assesses the degree to which illness perceptions and coping at diagnosis can predict variation in their experience of PTSD symptoms 6 months later (Richardson, Morton, & Broadbent, 2016c). The importance of this research is emphasised by describing the high rates of PTSD that have been documented among HNC caregivers, and the absence of studies examining variables that may help to explain its occurrence.

Chapter 7 presents the last findings from Study 1, obtained through a qualitative analysis of patient and caregiver responses to a number of open-ended questions regarding social and



psychological support needs at time of HNC diagnosis and again 6 months later. An inductive thematic approach was used to facilitate the coding of responses, which helped to determine the specific forms of support that would be most appreciated by patients and their caregivers at different points across the disease trajectory (Richardson, Morton, & Broadbent, 2015b).

Having revealed the importance of patient and caregiver illness perceptions and coping strategies to HNC patient and caregiver psychological outcomes, as well as a desire for psychological support among these individuals, the thesis turns to examine psychological interventions in Chapter 8. Interventions for patients with HNC that have been tested to date are described, in addition to common methodological problems associated with these studies. The dearth of interventions delivered at time of HNC diagnosis, and the absence of interventions that incorporate caregivers is identified. A rationale for investigating psychological interventions that target patient illness perceptions and coping is also provided; namely, that illness perceptions and coping are modifiable factors known to influence patient psychological outcomes following HNC treatment, and that research in a range of other patient groups has found interventions targeting these factors to be of great benefit, for both patients and their caregivers.

Chapter 9 provides results from Study 2 of this thesis, an investigation of a psychological intervention designed to modify illness perceptions and coping in patients with HNC and their caregivers. Intervention sessions were delivered by a health psychologist from time of diagnosis, and across the course of treatment, and their influence on patient HRQL and patient and caregiver psychological wellbeing was compared with standard care. Efforts were made to address limitations of previous research by utilising a randomised controlled design, and ensuring that the intervention tested was brief and coordinated around patient medical appointments, in order to minimise participant dropout. The study is the first to examine whether addressing illness perceptions and coping early after HNC diagnosis can improve psychological responses to treatment and promote recovery.

To conclude the thesis, Chapter 10 summarises the key findings from the two studies that were conducted and integrates these within the existing literature. The clinical implications are discussed, with an emphasis on improving the accessibility of psychological support for patients with HNC and their caregivers to enhance their HRQL and psychological wellbeing. Finally, limitations of the studies are acknowledged, leading to suggestions for future research directions.

Chapter 2. Head and Neck Cancer Background

Head and neck cancer is a physically and emotionally demanding disease, associated with challenging treatment, and long-term disturbances in function and appearance. In this chapter, a background to HNC is provided to highlight the distressing nature of symptoms and treatment, as well as the negative impact of HNC on patient and caregiver quality of life and psychological wellbeing. The high rates of depression and anxiety among affected individuals are identified, as well as the factors that may contribute to these. In particular, attention is paid to the role of illness perceptions and coping in response to diagnosis and treatment, with gaps in the literature emphasised to demonstrate the importance of further research in this area.

Patients

Prevalence and Incidence

Head and neck cancer is the sixth most prevalent cancer in the world, accounting for approximately 3% of all malignancies in the United States and 4% of those in Europe (Gatta et al., 2015; Siegel, Miller, & Jemal, 2015). Globally, nearly 600,000 people are diagnosed with HNC each year (Leemans, Braakhuis, & Brakenhoff, 2011). Cancers of the oral cavity are most common, accounting for 40% of new cases (Ferlay et al., 2008). By comparison, new diagnoses of cancers of the larynx, pharynx, and nasopharynx are less frequent (Simard, Torre, & Jemal, 2014).

In New Zealand, more than 500 cases of HNC are diagnosed every year (Ministry of Health, MOH, 2013). For example, there were 750 new HNC registrations in 2013; 690 of registered individuals were New Zealand European and 60 identified as Māori. Additionally, an estimated 200 cases of metastatic squamous cell skin cancer in the head and neck region are registered annually.

The incidence of HNC, particularly oral cancer, has been increasing over time. More men are diagnosed with HNC than women, with a male-female ratio of approximately 3:1 (Simard et al., 2014). The disease also occurs more frequently in developed countries than developing countries (Ferlay et al., 2008). Most diagnoses of HNC are made in older adults, particularly those aged over 50 years (Vander Walde, Fleming, Weiss, & Chera, 2013). Nevertheless, the number of young adults with oral cavity and oropharyngeal cancers is rising due to increased exposure to human papillomavirus (HPV) (Chaturvedi et al., 2013).

Cancer Sites and Symptoms

Symptoms of HNC vary according to the site at which the cancer occurs. Cancers of the oral cavity are those affecting the lips, gums, buccal mucosa, floor of the mouth, anterior of the tongue, and hard palate. Associated symptoms include a sore that does not heal, abnormal bleeding or pain in the mouth, swelling of the jaw, and discolouration of the gums, tongue, or lining of the oral cavity (Chong, 2005). If the cancer affects the salivary glands, symptoms may include swelling, numbness, and persistent pain under the chin or around the mandible (National Cancer Institute, NCI, 2013).

Conversely, symptoms associated with cancers of the pharynx and larynx include difficulty breathing or speaking, pain when swallowing, frequent headaches, and pain or ringing in the ears (Sasaki & Jassin, 2001). Cancers of the paranasal sinuses and nasal cavity can cause long-term blockage of the sinuses, epistaxis (bleeding from the nose), pain in the sinus areas, tooth pain, and problems with vision (Dirix, 2007). Other symptoms associated with cancers in the head and neck region include unexplained weight loss and fatigue, which may be partially explained by problems with eating (as a consequence of difficulty chewing, swallowing, or moving the jaw or tongue).

Treatment

Treatment of HNC is dependent on the type, location, and stage of the cancer, and may include any combination of surgery, radiotherapy, or chemotherapy. For patients who undergo surgical treatment, cancerous tissue is removed directly from the affected area of the head or neck, as well as other regions to which the cancer may have spread (Argiris et al., 2008). In contrast, radiotherapy involves the application of carefully directed and controlled high energy x-rays (NCI, 2016). With regards to chemotherapy treatment, medications that destroy cancer cells are delivered to the patient orally or intravenously. Surgery and radiotherapy are the only curative treatments for HNC. However, when the disease is of an advanced stage (III-IV), or there is involvement of lymph nodes in the neck, chemotherapy is combined with radiotherapy in an effort to improve patient survival and decrease cancer-related symptoms.

Surgery

Surgical resection of HNC can take many hours and typically requires a hospital stay ranging from several days to several weeks. It is often difficult for patients to eat or drink in the days following their surgery due to swelling in the mouth and throat area. In such cases, either a gastrostomy tube

(passed through the abdomen into the stomach) or a nasogastric tube (passed through the nose, down the oesophagus, and into the stomach) is inserted (Rustom, Jebreel, Tayyab, England, & Stafford, 2006). Swelling can also restrict the airway making it hard for patients to breathe. This creates a need for a tracheostomy or stoma, a small opening in the windpipe, until the swelling subsides. Speech can be permanently altered following HNC surgery. This most commonly occurs among patients who have had a laryngectomy, which involves partial or complete removal of the larynx, and requires a permanent stoma in the neck. Other side effects of HNC surgery include lasting pain and discomfort, altered sensation (numbness), difficulty opening the mouth, and severe facial disfigurement (Marur & Forastiere, 2008). Reconstructive surgery is frequently necessary, whereby tissue or bone is taken from other areas of the body to replace that removed from the head and neck. Prosthetics may also be offered to patients for whom bones (such as the cheekbone or palate) have been removed from the face (Tang, Rieger, & Wolfaardt, 2008).

Radiotherapy

Radiotherapy typically takes place once or twice a day, five days a week, for a period of 5-7 weeks. To ensure that patients conform to a specific position during their treatment sessions, they must wear a plastic mesh mask over the face that is attached to the table on which they lie. Although this allows for the delivery of targeted treatment, it is not uncommon for patients to experience claustrophobia while restricted by the mask (Kim et al., 2004). Furthermore, radiotherapy causes inflammation of the mucous membranes lining the mouth and throat resulting in ulceration, discomfort, and pain when swallowing (Trotti et al., 2003). These side effects intensify with every radiotherapy session. For some patients the resultant pain severely limits their ability to eat and drink causing significant nutritional deficiencies and drastic weight loss. In such cases, patients must have a gastrostomy tube temporarily inserted into the stomach to ensure that they maintain adequate nutrition. Other side effects of radiotherapy include dryness of the mouth, thickened saliva, redness and irritation of the skin, loss of taste and smell, and tooth decay (NCI, 2016).

Chemotherapy

Chemotherapy is administered concurrently with radiotherapy and, consequently, treatment toxicity and associated side effects are exacerbated (Machtay et al., 2008). This approach can result in nausea and vomiting, fatigue, hair loss, diarrhoea, reduced appetite, mouth sores, and a heightened

risk of infection in the short-term (Trotti et al., 2003). In the long-term, side effects may include inflammation and ulceration of mucous membranes lining the digestive tract, difficulty swallowing, and dependence on a gastrostomy tube (Mason et al., 2016).

Multidisciplinary Team

Due to the complexity of treatment for HNC, input from a number of different specialties is required to maximise patient physical and psychological outcomes (Argiris et al., 2008). In addition to the care provided by surgeons, oncologists, radiologists, pathologists, and nurses, patients also receive support from dieticians, speech and language therapists, dental specialists, and social workers. These professionals comprise a multidisciplinary team whose function is to develop a treatment plan that will optimise survival while preserving patient quality of life. The collaboration of these specialties has been found to promote adherence to best practice (Kelly, Jackson, Hickey, Szallasi, & Bond, 2013), and improve survival for patients with advanced HNC (Friedland et al., 2011). However, most multidisciplinary teams caring for patients with HNC do not include a psychologist, despite symptoms and treatment of the disease having significant implications for patient self-image and psychological wellbeing (Hodges & Humphris, 2009).

Survival

For most patients, a diagnosis of HNC presents a significant threat to mortality. The overall 5-year survival rate is between 50% and 60%, which is low relative to other types of cancer (Ries et al., 2006). Furthermore, limited improvement in this survival rate has been observed over time (Jemal, Thomas, Murray, & Thun, 2002). Approximately 350,000 deaths are attributable to HNC every year worldwide (Argiris et al., 2008). In New Zealand, Māori patients have lower survival than non-Māori patients. Between 1991 and 2004, Māori had 37% greater excess mortality compared to non-Māori (MOH, 2012). Socioeconomic deprivation was associated with patient survival across this time period, with HNC patients in the lowest income quintile experiencing 28% greater excess mortality than patients in the highest income quintile.

Survival following an HNC diagnosis is dependent on stage of disease at presentation, with more advanced cancer associated with worse survival (Ringash, 2014). Approximately 30% of patients present with an early stage cancer (stage I-II), while 70% have a late (or advanced) cancer (stage III-IV). For 10% of patients who present with advanced cancer, the cancer has metastasised to distant

areas of the body and is incurable. Late presentations are common among patients with HNC, largely because the disease is difficult to detect in primary care settings (Alho, Teppo, Mantyselka, & Kantola, 2006).

Survival is also significantly reduced among patients with HNC who develop a recurrence. Cancer recurrence occurs in at least 50% of patients initially diagnosed with late stage HNC (Argiris et al., 2008), and is untreatable in most cases, resulting in a median survival of 6 months (Vermorken & Specenier, 2010). Furthermore, patients with HNC are susceptible to the development of second primary cancers outside the head and neck, and comorbid illnesses (particularly cardiovascular disease), which place these individuals at increased risk of death relative to the general population (Ringash, 2014).

Risk Factors

The factors most strongly linked with the development of HNC are cigarette smoking and alcohol consumption, with these behaviours working synergistically to increase risk of the disease (Maasland, van den Brandt, Kremer, Goldbohm, & Schouten, 2014). The rate of HNC is six times greater in smokers relative to non-smokers (Do et al., 2003), and there are well-documented dose-response relationships between the incidence of HNC and frequency, duration, and number of pack-years smoking (Hashibe et al., 2007). High levels of alcohol consumption have also been linked to increased HNC risk, even in individuals who have never smoked cigarettes (Moyses et al., 2013). However, alcohol consumption and cigarette smoking often co-occur in patients with HNC (Mayne, Cartmel, Kirsh, & Goodwin, 2009). Engaging in these behaviours prior to diagnosis and thereafter is associated with multiple medical comorbidities (Curado & Hashibe, 2009), and predicts poorer response to treatment, as well as reduced survival (Pytynia et al., 2004).

Other factors associated with an increased risk of HNC include previous infection with HPV or Epstein-Barr virus (EBV), diet, and genetic susceptibility. A strong epidemiologic link has been established between HPV and oropharyngeal cancer (Sturgis, Wei, & Spitz, 2004), with approximately 60% of oropharyngeal cancers in the United States testing positive for the HPV subtype HPV-16 (Marur, Souza, Westra, & Forastiere, 2010). Conversely, infection with EBV has been linked to the subsequent development of nasopharyngeal cancer (Raab-Traub, 2015). Case-control studies have also demonstrated that diets high in animal fats and low in fruits and vegetables increase HNC risk

(Maasland, van den Brandt, Kremer, Goldbohm, Schouten, 2015), and that a family history of HNC in first-degree relatives is associated with greater likelihood of developing the disease (Negri et al., 2009).

Patient Quality of Life

Quality of life concerns are of principal importance among patients with HNC. Not only does the disease affect basic functions (including the ability to speak, swallow, and breathe) and the senses (taste, smell, and hearing), but also characteristics unique to an individual, such as voice quality and appearance (Pfister et al., 2011).

The term quality of life encompasses a collection of physical and psychological attributes that index a person's capacity to function and to derive satisfaction from such function (Morton & Izzard, 2003). Health-related quality of life specifically considers how such factors are impacted over time by a disease, disability, or disorder. Domains of HRQL are typically divided into physical/functional, social, emotional, and general wellbeing (Ojo et al., 2012). In contrast to other outcomes (e.g. health status), the central focus of HRQL is the subjective *value* placed on various aspects of health and function, which can only be determined by the patient alone (Pfister et al., 2011).

Assessment

The assessment of HRQL in patients with HNC enables researchers and clinicians to capture patient perceptions of the way in which the disease impacts upon different aspects of wellbeing. This information can be used to evaluate the effectiveness of different treatments, benefits of palliative care, and quality of patient survival. Patient-completed questionnaires are recommended for the valid assessment of HRQL (Pfister et al., 2011). Numerous multidimensional questionnaires have been developed to assess HRQL specifically in patients with HNC (Ojo et al., 2012), although the three most widely used and psychometrically sound measures include: the University of Washington Quality of Life Scale (UW-QOL; Rogers et al., 2002), the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC-QOL; Bjordal et al., 1999), and the Functional Assessment of Cancer Therapy-Head and Neck module (FACT-H&N; Cella et al., 1993). Responses to these measures can guide improvements in patient care and life satisfaction by making it possible to individually tailor treatment and rehabilitation (Morton, 2012).

Quality of Life Impact of Head and Neck Cancer

Assessments of HRQL have led to an improved understanding of how this outcome varies among patients with HNC over time. Patients with HNC report the lowest HRQL during and immediately after treatment, following which HRQL gradually improves (de Graeff et al., 2000a; Hammerlid, Silander, Hornestam, & Sullivan, 2001). Typically, HRQL levels approach those reported prior to treatment approximately 12 months after diagnosis (Gritz et al., 1999). However, there is substantial variation in this trajectory among individual patients (Llewellyn, McGurk, & Weinman, 2006a), with some regaining normal function soon after their treatment, and others experiencing long-term problems, including eating and dental difficulties, persistent pain, and reduced life satisfaction (Abendstein et al., 2005; Funk, Karnell, & Christensen, 2012; Mehanna & Morton, 2006). The experience of functional limitations related to HNC and its treatment do not necessarily translate to poor HRQL (Hammerlid & Taft, 2001), highlighting the importance of research to determine factors that lessen the impact of enduring symptoms on recovery. Relative to other types of cancer, investigations to identify these factors among patients with HNC are sparse.

Physical, Social, and Emotional Functioning

Head and neck cancer has been found to negatively impact every aspect of patient HRQL, including physical, social, and emotional wellbeing. The majority of studies have examined physical difficulties post-treatment, which are xerostomia (dry mouth), problems opening the mouth, and thickened saliva (Abendstein et al., 2005), as well as hoarseness, choking, and phlegm in the throat (de Boer et al., 1995), taste dysfunction (Alvarez-Camacho et al., 2016), dental decay (Duke et al., 2005), and long-term pain (Chaplin & Morton, 1999).

In contrast, relatively few studies have investigated the social aspect of patient HRQL (Babin et al., 2008). There is evidence to suggest that the impact of HNC on function and appearance has a negative influence on patients' social interactions and family relationships. For example, the inability to speak intelligibly following treatment can lead to changes in self-perception and social withdrawal (Roing, Hirsch, & Holmstrom, 2007). Similarly, patients who sustain extensive disfigurement from their treatment are more likely to report a worsened relationship with their partner, reduced sexuality, and increased social isolation compared to those who sustain minor disfigurement (Gamba et al., 1992).

A diagnosis of HNC also has a strong effect on emotional functioning, with high levels of psychological distress consistently documented among patients (Bjordal & Kaasa, 1995; Haisfield-Wolfe, McGuire, Soeken, Geiger-Brown, & De Forge, 2009; Neilson et al., 2013). The basis of this distress is thought to be multifaceted and may be attributed to the diagnosis itself, functional and social problems associated with the disease, declines in global quality of life, or the high chance of recurrence or death (Howren et al., 2013). The challenges faced by patients with HNC have led to the suggestion that the cancer is one of the most emotionally traumatic an individual can experience (Bjorklund, Sarvimaki, & Berg, 2010).

Quality of Life and Survival

Health-related quality of life is consistently identified as a predictor of HNC patient mortality, independent of sociodemographic and clinical parameters (Abendstein et al., 2005; Oskam et al., 2010). Thompson and colleagues (2011) found that the likelihood of death from HNC was four times lower in patients reporting high overall quality of life than for those reporting low overall quality of life. Evidently, the importance of HRQL in patients with HNC cannot be ignored, and efforts to improve this outcome are likely to eventuate in benefits for patient survival.

Patient Psychological Distress

Psychological distress is understood as an unpleasant emotional experience characterised by a combination of symptoms, including cognitive and behavioural impairments (Neilson et al., 2013). All patients experience some degree of distress in response to a diagnosis of cancer (Howell & Olsen, 2011), with this distress existing on a continuum that ranges from typical transient feelings of fear, sadness, and vulnerability to more severe and enduring problems, such as depression, anxiety, panic, and social isolation (National Comprehensive Cancer Network, NCCN, 2011). Given the distinct and serious implications of their diagnosis and treatment, patients with HNC are more susceptible to severe forms of psychological distress than patients with other types of cancer.

General Distress

Approximately 50% of patients with HNC experience distress at any given point in the disease trajectory (de Leeuw et al., 2001; Howren et al., 2013; Karnell, Funk, Christensen, Rosenthal, & Magnuson, 2006; Sehlen et al., 2003). The prevalence of distress among patients with HNC exceeds

that of patients with any other cancer. Singer et al. (2012) found that patients with HNC were more frequently distressed than patients with breast, gynaecological, prostate, urologic, gastrointestinal, lung, brain, and other cancers at time of admission to hospital, before discharge, and 6 months after admission. The difference in distress frequency was only partially explained by differences in treatment modality. Instead, social context accounted for greater distress among patients with HNC, who were less likely to request and receive social support compared to patients with other cancer types.

Depression

Severe symptoms of psychological distress may meet criteria for a psychiatric diagnosis (Neilson et al., 2013). One such diagnosis is major depressive disorder, which is characterised by persistent feelings of sadness and anhedonia. To receive a diagnosis of depression based on criteria specified in the Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5), an individual must exhibit five or more symptoms that include either depressed mood or loss of interest and/or pleasure over a consecutive period of at least 2 weeks (American Psychiatric Association, APA, 2013). These symptoms must be accompanied by significant impairment in social, occupational, or other functional domains.

Among patients with HNC, depressive symptoms are common at diagnosis, during treatment, and in the first 6 months post-treatment (Haisfield-Wolfe et al., 2009). Symptoms have been found to continue at mild to moderate levels for 3-6 years after diagnosis, and are detected as many as 11 years post-treatment (Bjordal & Kaasa, 1995). In a cross-sectional study of 973 patients with HNC, 46% screened positive for depressive symptoms, even after adjusting for important clinical and demographic variables (Duffy et al., 2007). These symptoms are unlikely to be pre-existing; high rates of depressive symptoms have been noted among HNC patients with no previous history of a mood disorder or mental health service use (Chen et al., 2013). This suggests that depression may occur as a direct response to HNC diagnosis and subsequent treatment sequelae.

It is important to note that estimates of the prevalence of depression vary based on method of assessment. While some studies have aimed to detect the presence of depressive disorders (utilising structured clinical interviews), most have investigated depressive symptoms (utilising self-report measures). The prevalence of depressive symptoms is higher than the prevalence of depressive disorders in patients with HNC (Archer, Hutchison, & Korszun, 2008). However, depressive disorders

are more common among HNC patients than the general population (Katz, Kopek, Waldron, Devins, & Tomlinson, 2004b; Kugaya et al., 2000; McCaffrey et al., 2007; Morton, Davies, Baker, Baker, & Stell, 1984), and individuals with other forms of cancer (Massie, 2004). An elevated rate of suicide has also been noted in patients with HNC, with these patients 1.5 times more likely to commit suicide than the wider cancer population (Zeller, 2006).

Anxiety

High rates of anxiety have also been documented in patients with HNC (Howren et al., 2013). Although anxiety is commonly regarded as a natural response to stressful life events, anxiety becomes pathological when it is excessive and uncontrollable, requires no specific external stimulus, and is associated with a number of physical and affective symptoms (APA, 2013). These include excessive nervousness and worry, irritability, fatigue, muscle tension and restlessness, trouble sleeping, and some forms of cognitive dysfunction (such as memory and concentration difficulties).

While there is some evidence to suggest that anxiety is highest at HNC diagnosis (Hammerlid et al., 1999a; Neilson et al., 2010), other research has found that high levels of anxiety can also be detected post-treatment. A prospective study examining psychological distress in HNC patients who received radiotherapy found that 22% met probable caseness for anxiety at 18 month follow-up, in comparison to 20% at diagnosis and 17% at 3 weeks post-treatment (Neilson et al., 2013). Females exhibit higher levels of anxiety than males at diagnosis (de Boer et al., 1995), and patients under 65 years are typically more anxious than patients aged over 65 (Hammerlid et al., 1999a). Anxiety is more prevalent than depression at time of diagnosis (Pandey et al., 2007), whereas depression is most common during HNC treatment (Hammerlid et al., 1999a).

Post-Traumatic Stress

Post-traumatic stress disorder is a psychiatric disorder that can occur in response to exposure to a traumatic event, including actual or threatened death, serious injury, or sexual violation (APA, 2013). In order to meet criteria for this disorder a person must demonstrate symptoms related to four distinct clusters: re-experiencing of the traumatic event (memories, flashbacks, or dreams); avoidance of reminders of the event; negative cognitions and mood; and heightened arousal. A diagnosis of cancer has been identified as a traumatic event capable of eliciting PTSD by the American Psychiatric Association (APA, 1994). Patients with HNC may be at particular risk of developing PTSD. In addition

to receiving a life-threatening diagnosis, patients are faced with the prospect of highly distressing treatment that has potential to produce long-term impairments in bodily function and facial disfigurement.

Only two studies have investigated the prevalence of PTSD in patients with HNC. The first of these found that 22% of a mixed sample (including patients with HNC and patients with lung cancer) met criteria for the disorder 6 months after diagnosis (Kangas, Henry, & Bryant, 2005a). A high level of distress at diagnosis was the best predictor of subsequent PTSD caseness. Furthermore, 14% of patients continued to experience PTSD at 12 month follow-up, despite high rates of participant attrition (Kangas, Henry, & Bryant, 2005b). Similar results were obtained by Posluszny and colleagues (2015), who found that 12% of newly diagnosed HNC patients had PTSD.

Distress Screening

The NCCN recommends screening all patients with cancer for distress in order to identify those who would benefit from psychological support. Available evidence suggests that screening is an effective method for facilitating the delivery of targeted support services and improving patient psychological wellbeing. For example, patients with breast and lung cancer who received a referral to psychological services following distress screening demonstrated reductions in depression and anxiety over time (Carlson, Groff, Maciejewski, & Bultz, 2010). Despite this, distress screening rarely occurs in clinical practice. Consequently, distress is often unreported by patients and undetected by clinicians (Pirl et al., 2007).

Although the prevalence of psychological distress is highest among HNC patients, research suggests that distress is less likely to be recognised in this group than it is in patients with other types of cancer. In their study investigating oncologists' ability to identify patient distress and need for psychological counselling, Sollner and colleagues (2001) found that distress was recognised by oncologists in only 11 of 30 severely distressed patients. Furthermore, oncologist perceptions of distress were most frequently incorrect for patients with HNC. The physical morbidity caused by HNC and its treatment, particularly disfigurement and related dysfunction, can be unique barriers to the detection of distress (Katz et al., 2004b). This is largely due to the problems such factors present for patient communication and emotional expression, and may be one reason why mental health services are significantly underutilised by patients with HNC (Chen et al., 2013).

Patient Distress and Outcomes

Failure to detect distress in patients with HNC is concerning in light of the implications this has for patient psychological wellbeing and overall health. Untreated distress, particularly symptoms of depression and anxiety, have been found to detrimentally influence a wide range of outcomes in patients with HNC, including fear of cancer recurrence (Hodges & Humphris, 2009; Ghazali et al., 2013), physical functioning (de Graeff et al., 2000b), global and disease-specific HRQL (e.g. Hammerlid et al., 2001; Kelly, Paleri, Downs, & Shah, 2007; Kohda et al., 2005; Llewellyn et al., 2006a), and prognosis (Aarstad, Aarstad, Heimdal, & Olofsson, 2005). For example, low mood was prospectively related to continued dysfunction in eating, diet, and speech in a study of 105 individuals with cancer of the oral cavity, pharynx, or larynx (Gritz et al., 1999). Similarly, Howren and colleagues (2010) demonstrated that the presence of subclinical depressive symptoms prior to HNC treatment was associated with worse patient HRQL at 1 year follow-up (even when controlling for baseline HRQL, age, gender, marital status, disease site and stage, alcohol and tobacco use, and physical comorbidities).

More recently, pre-treatment depression has been linked to lower survival in patients with HNC (Kim et al., 2016). Patients who met criteria for depression on the Beck Depression Inventory (BDI; Beck, Steer, & Brown, 1996) prior to treatment had a 3 year overall survival rate of 70.8% compared to 82.7% in patients not classified as depressed. Depressed individuals also had a lower rate of disease free survival (63.5% compared to 79.1%), which remained when controlling for clinical factors. Such findings are consistent with research demonstrating that depression (both prior to and following diagnosis) is predictive of mortality in patients with cancer (Pinquart & Duberstein, 2010; Satin, Linden, & Phillips, 2009).

The above findings underscore the need to address the high rates of psychological distress in patients with HNC, not only in order to improve psychological wellbeing but also to facilitate overall adaptation and physical recovery from the disease.

Predictors of Quality of Life and Psychological Distress

Given the severe impact of HNC on physical and psychological wellbeing, it is important to determine the factors that make patients vulnerable to poor outcomes following their diagnosis and treatment. This would allow for the identification of patients at risk of experiencing these outcomes,

who may benefit from psychological interventions. While several variables that predict variation in patient distress and HRQL have been identified, research in this area is limited (Murphy, Ridner, Wells, & Dietrich, 2007). Furthermore, a recent review concluded that due to methodological shortcomings associated with available studies (including problems with study design, participant recruitment, and statistical analysis), there is an absence of high-quality research investigating psychological factors that contribute to adjustment in patients with HNC (Dunne et al., 2016).

Demographic and Medical Characteristics

Demographic characteristics have been associated with psychological distress in patients with HNC. A number of studies have found that patients who are younger (Derks, de Leeuw, Winnubst, & Hordijk, 2004; Reisine et al., 2005), male (Katz et al., 2004b), live alone or are unmarried (Kugaya et al., 2000), experience social disruption (Karnell, Christensen, Rosenthal, Magnuson, & Funk, 2007), and have a low level of education (Sehlen et al., 2003) report the highest rates of depression. Medical factors, including HNC-related physical symptoms and cancer stage, are also closely related to patient distress. A greater number of symptoms and more advanced cancer stage have been found to predict greater depression and anxiety several years post-treatment (de Leeuw et al., 2001; Kugaya et al., 2000; Neilson et al., 2013).

With respect to HRQL, baseline HRQL scores are the strongest predictor of this outcome (El-Deiry, Futran, McDowell, Weymuller, & Yueh, 2009). However, medical variables also make a contribution. Cancer stage was a strong negative predictor of HRQL in a study involving 570 patients with upper aerodigestive tract cancers (Terrell et al., 2004). Treatment type has been found to differentially affect HRQL (Morton & Izzard, 2003). Patients who receive both surgery and radiotherapy report worse overall function than those who receive a single modality treatment (Hassanein, Musgrove, Bradbury, 2001). Nevertheless, the percentage of variation in HRQL that can be explained by medical factors is relatively small (Hammerlid et al., 2001). Depressive symptoms at diagnosis have been found to make a stronger contribution to this outcome than performance status, cancer site and stage, and treatment type (de Graeff et al., 2000b).

Individual Differences

Despite relationships between demographic and medical characteristics and the psychological wellbeing and HRQL of patients with HNC, there is substantial unexplained variation in these outcomes

(Howren et al., 2013). It is likely that individual differences in responding to the stress of diagnosis, treatment, and symptoms have a large influence on patient adaptation to the disease. Few studies have investigated the role of such differences in patients with HNC. However, numerous studies in other patient groups suggest that it is important to consider the way in which individuals perceive and cope with their diagnosis and treatment (Dempster, Howell, & McCorry, 2015).

Illness Perceptions

It is widely accepted that psychological factors, including patient perceptions of illness, are major determinants of health-related behaviour. Leventhal and colleagues (1980) first introduced the concept of illness perceptions, proposing the common sense model of self-regulation (CSM). According to the model, patients hold beliefs (or representations) about their illness which influence the adoption of coping behaviours (Myer, Leventhal, & Gutmann, 1985). These behaviours then guide appraisals of health (see Figure 1). Representations of illness are shaped by a range of sources, including previous social communications, cultural knowledge, information from individuals perceived as authoritative sources (such as medical professionals), and prior experiences of illness (Hagger & Orbell, 2003). As patients obtain new information and evaluate the effectiveness of their coping attempts, illness representations may be modified; that is, adopted, discarded, or adapted as necessary (Hale, Treharne, & Kitas, 2007).

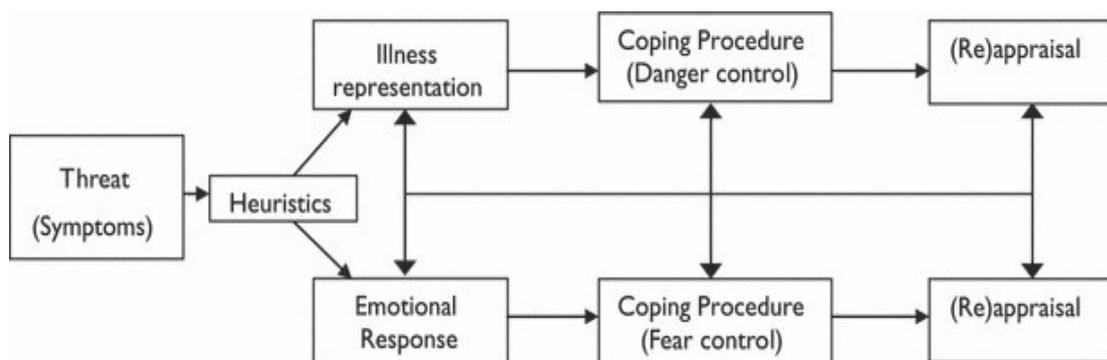


Figure 1. Leventhal's common sense model of self-regulation (CSM) (Scott, Walter, Webster, Sutton, & Emery, 2013), reproduced with permission.

The CSM is a parallel processing model in which patients simultaneously hold cognitive and emotional representations of their illness (Leventhal, Nerenz, & Steele, 1984). Research has established that cognitive representations of illness include perceptions of *identity* (the label and

symptoms associated with a condition), *timeline* (illness chronicity), *consequences*, *causes*, *personal control* over the illness, the extent to which the illness can be *cured or controlled*, and illness *coherence* (or understanding). Emotional representations include perceptions of *emotional impact* and level of *concern* generated by the illness (Leventhal, Diefenbach, & Leventhal, 1992).

There is a large evidence base linking components of the CSM to health outcomes (including disease state, physical function, role function, psychological distress, general wellbeing, and vitality) in a broad range of patient groups (Hagger & Orbell, 2003). However, few studies have investigated illness perceptions specifically in patients with HNC. The CSM is likely to be applicable to this patient group given that relationships between the illness perceptions of patients with other forms of cancer and subsequent psychological distress are well-documented in the literature (Kaptein et al., 2015; Richardson, Schuz, Sanderson, Scott, & Schuz, 2016d). Illness perceptions have also been found to predict HRQL in patients with cancer (Dempster et al., 2015). In a study of 334 breast, colorectal, and prostate cancer patients, those who reported a belief that the cancer would have a serious negative impact on their life within 6 months of diagnosis reported the worse HRQL at 15 month follow-up (Ashley, Marti, Jones, Velikova, & Wright, 2015).

The majority of studies examining relationships between illness perceptions and outcomes in patients with HNC are limited due to their cross-sectional nature. Scharloo and colleagues (2005) found that for 68 patients yet to receive treatment, illness perceptions were significantly related to physical, role, emotional, cognitive, and social functioning, even after controlling for comorbidity. Perceiving many symptoms and a strong emotional impact of HNC was most strongly associated with poor functional capacity. Similar findings were reported in a study whereby illness perceptions were associated with choice of coping among 82 newly diagnosed HNC patients (Llewellyn et al., 2007a). Specifically, negative perceptions with respect to consequences, concern, and emotional impact of HNC were related to the use of less effective coping strategies (denial, substance use, venting, and self-blame). These strategies, in turn, were associated with lower patient HRQL. Conversely, perceiving a high level of personal control was related to the use of active coping strategies (planning, active coping, and positive reframing), which were associated with higher self-reported HRQL. Illness perceptions have also been linked to symptoms of depression and anxiety in a large sample of oesophageal cancer patients at varying stages post-treatment (Dempster et al., 2011a). Patients who perceived many severe consequences, low personal control, and little understanding of their condition reported the highest number of symptoms.

To date, only three studies have investigated the *longitudinal* relationship between illness perceptions and psychological outcomes in patients with HNC. Scharloo and colleagues (2010) found that perceiving many symptoms at HNC diagnosis predicted worse physical function and global health 2 years later, while less belief in one's own behaviour causing the disease predicted better function and global health at this time point. Contrary to these findings, an investigation involving 50 HNC patients did not find illness perceptions at diagnosis to be predictive of HRQL or anxiety 6-8 months post-treatment (Llewellyn et al., 2007b). However, perceptions of long illness duration (timeline) did predict post-treatment depression symptoms. Finally, a study conducted in the post-treatment phase found that reductions in perceptions of personal and treatment control were associated with increases in depression and anxiety symptoms over time among 189 patients with oesophageal cancer (Dempster et al., 2011b).

While these studies suggest that illness perceptions may play an important role in patient recovery from HNC, it is not possible to draw strong conclusions. Most research to date has been cross-sectional. Therefore, it is unclear as to whether findings would be documented at different stages of the disease, and whether illness perceptions have the capacity to predict variation in future outcomes. Indeed, only two studies have investigated the predictive power of illness perceptions at time of diagnosis. More research at this time point is needed to clarify whether illness perceptions can influence subsequent patient psychological distress and HRQL. Such research would highlight the importance of identifying patients with maladaptive perceptions at HNC diagnosis, and help to determine whether there is utility in developing psychological interventions that promote long-term adjustment.

Coping

The high levels of psychological distress evident in patients with HNC have also been associated with ways of coping with diagnosis and treatment. The most widely accepted conception of coping is based on the theoretical framework of Lazarus and Folkman, who define coping as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p.41). Specifically, coping behaviours are employed to deal with stress, which occurs when environmental stimuli are perceived to be damaging, threatening, or challenging. Coping is thought to

result from a combined interaction of cognitive activity, emotions, and physiological responses (Scott, Oberst, & Dropkin, 1980).

Coping is a multidimensional construct (Skinner, Edge, Altman, & Sherwood, 2003). An important distinction in the coping literature is between problem-focused and emotion-focused coping (Folkman & Lazarus, 1980). Problem-focused coping incorporates the use of strategies directed at actively managing or removing a stressor, such as planning, information seeking, or problem solving. In contrast, emotion-focused coping involves using techniques to minimise emotional distress associated with a stressor, such as cognitive reappraisal, self-reflection, or relaxation. The effectiveness of problem-focused or emotion-focused coping strategies is dependent on situational factors. Problem-focused coping is most appropriate for stressors that are perceived to be controllable by an individual, whereas emotion-focused coping is most beneficial when a stressor is not perceived as controllable (Carver & Connor-Smith, 2010).

Another important coping distinction can be made between strategies characterised by engagement/approach and those characterised by disengagement/avoidance (Skinner et al., 2003). Engagement coping strategies refer to those aimed at directly addressing a stressor, either by changing the nature of the stressor itself or by altering the way one thinks or responds to the stressor. In contrast, disengagement coping strategies involve avoidance of the stressor and its associated emotional impact. Avoidance can be characterised by both cognitive (e.g. denial) and physical behaviours (e.g. substance use). The use of disengagement coping strategies is typically recognised as a maladaptive response to stress (Carver & Connor-Smith, 2010).

The relationship between coping behaviours and physical and psychological outcomes among patients with HNC has primarily been investigated in the post-treatment phase. This is despite the potential for coping prior to treatment to influence adaptation and recovery from the disease (Howren et al., 2013). The use of disengagement/avoidant coping has consistently been associated with lower HRQL and greater psychological distress in patients successfully treated for HNC (Aarstad, Beisland, Osthus, & Aarstad, 2011a). For example, coping by avoidance at 3 years post-diagnosis has predicted lower HRQL scores 3 years later (Aarstad, Aarstad, & Olofsson, 2008). Elani and Allison (2011) found that avoidant coping 6-12 months post-diagnosis was associated with higher levels of anxiety and depression in 157 HNC patients, after demographic, disease, and treatment-related factors were controlled for. High levels of coping by avoidance, drinking to cope, and high alcohol consumption have

also predicted greater distress following HNC treatment (Aarstad, Beisland, & Aarstad, 2012; Aarstad, Lode, Larsen, Bru, & Aarstad, 2011b).

There is evidence to suggest that HNC patients who have recently completed treatment are more likely to exhibit denial, behavioural disengagement (i.e. giving up or withdrawing), and emotional venting compared with patients who are in later phases of illness (Sherman, Simonton, Adams, Vural, & Hanna, 2000). This may reflect the aim of patients to accommodate the stress associated with treatment-related impairments, largely by distancing themselves from their experience. Post-treatment has been identified as a particularly difficult time for HNC patients due to their contention with severe treatment side effects while receiving less support from medical staff (Wells, 1998).

Another coping strategy that has been associated with deleterious effects in patients with HNC is that of helplessness/hopelessness (Hassanein et al., 2001; Kugaya, Akechi, Okamura, Mikami, & Uchitomi, 1999). Patients who use this strategy perceive their illness as overwhelming and, consequently, 'give up' on any hope of recovery. One investigation found that helplessness was the most commonly used method of coping by patients with oral and laryngeal cancers (Chaturvedi, Shenoy, Prasad, Senthilnathan, & Premlatha, 1996). Patients who reported a sense of helplessness regarding their diagnosis and treatment had an increased likelihood of depression or anxiety. Similarly, a longitudinal study involving 95 patients with laryngeal cancer demonstrated a relationship between a helpless/hopeless response one month after treatment and higher anxiety and depression, decreased HRQL, and poorer survival at 12 month follow-up (Johansson, Ryden, & Finizia, 2011).

Although several studies have examined post-treatment coping in patients with HNC, very few have investigated coping behaviours at time of diagnosis. Furthermore, the majority of studies that have investigated pre-treatment coping have been cross-sectional (Horney et al., 2011; List et al., 2002), preventing inferences about the causal direction by which coping variables are related to psychological outcomes. Only two longitudinal studies have examined relationships between coping at HNC diagnosis and future patient HRQL and psychological distress. Llewellyn and colleagues (2007b) showed that high levels of acceptance coping at diagnosis were negatively related to global quality of life and positively related to depression 6-8 months post-treatment. High levels of self-blame were also predictive of subsequent depression scores. Derks et al. (2005) found that avoidance coping was associated with worse HRQL and more depressive symptoms at diagnosis and again at 6 and 12 month follow-up.

Previous research also suggests that a bidirectional relationship exists between ineffective coping strategies and poor psychological outcomes. Pre-treatment depression among patients with HNC has been cross-sectionally related to helplessness/hopelessness, fatalism, and avoidant coping (Chaturvedi et al., 1996; Derks et al., 2005; Kugaya et al., 1999), while pre-treatment anxiety is associated with reduced engagement in adaptive preoperative and postoperative coping (Dropkin, 2001). These findings suggest that not only does the use of disengagement coping strategies result in higher levels of psychological distress, but pre-existing psychological distress can affect the ability of patients to cope effectively with HNC. Further research is necessary to examine such associations over time, with a particular focus on whether coping strategies at diagnosis can predict post-treatment outcomes, even when psychological distress at baseline is accounted for. Evidence to this effect would provide a rationale for identifying HNC patients using disengagement coping, who may benefit from psychological interventions designed to modify coping behaviours in an effort to promote future HRQL and psychological wellbeing.

Preliminary evidence suggests that the use of engagement coping strategies is associated with positive recovery outcomes in patients with HNC, namely, self-care and benefit finding. Self-care involves behavioural changes with respect to diet and lifestyle (for example, alcohol avoidance, regular exercise, adequate rest). This method of coping has been found to precede reductions in anxiety among HNC patients expecting to sustain facial disfigurement (Dropkin, 2001). The use of engagement coping strategies is also related to benefit finding in this patient group (Cavell, Broadbent, Donkin, Gear, & Morton, 2016); that is, the identification of positive outcomes from an adverse situation. Positive reappraisal was associated with increased benefit finding in a cross-sectional study of 76 patients previously treated for HNC (Harrington, McGurk, & Llewellyn, 2008), and use of emotional support and active coping strategies prior to treatment predicted benefit finding 6 months after treatment among 103 newly diagnosed HNC patients (Llewellyn et al., 2013).

Caregivers

Patients with HNC rely heavily on the support of informal caregivers to manage the physical and psychological challenges associated with the disease (Longacre et al., 2012). Informal caregivers can be defined as family members and close friends of a patient who provide any form of physical or emotional care. This might include assistance with medical tasks and appointments, meal preparation, household management, transportation, as well as the provision of information and emotional support

(Ross, Mosher, Ronis-Tobin, Hermele, & Ostroff, 2010). As a result, caregivers are often exposed to a diverse range of stressors, such as changes in family roles and daily routines, disrupted work schedules, and financial and emotional strain (Gaugler et al., 2005).

Although many studies have investigated psychological distress in patients with cancer, research regarding the mental health and wellbeing of their caregivers has been comparatively sparse. Available evidence suggests that caregivers report high levels of psychological distress and burden and poor subjective wellbeing and physical health in comparison to noncaregivers (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Pinquart & Sorensen, 2003). Caring for a family member with cancer places an individual at particularly high risk of distress (Mazzotti, Sebastiani, Antonini Cappellini, & Marchetti, 2013). A study of 310 caregivers of patients with cancer found that 67% met the threshold for depression as assessed by the BDI, and 35% had scores indicative of severe depression (Rhee et al., 2008).

Caring for a patient with HNC is a different experience to caring for a patient with another chronic illness due to the functional impairments associated with the disease (Vickery, Latchford, Hewison, Bellew, & Feber, 2003). Caregivers assist patients to manage negative changes in facial appearance, social/emotional expression and communication, and a reduced ability to eat, drink, swallow, taste, and breathe. Caregivers report a sense of responsibility to closely monitor and promote patient health status, with a particular focus on food intake; almost all patients experience dramatic weight loss and nutritional deficits following HNC treatment (Nguyen, Moltz, & Frank, 2004). In order to encourage patients to eat, caregivers place much thought, activity, and time into the preparation of meals, taking into account nutritional content, texture, and patient food preferences (Patterson, Rapley, Carding, Wilson, & McColl, 2013). Caregivers can experience significant guilt in being able to eat and enjoy food which can result in them restricting their own diets, and endeavouring to eat in the absence of the patient (Schaller, Liedberg, & Larsson, 2014). Furthermore, patient difficulties related to the consumption of food have been found to impact caregiver social activities (such as participation in shared meals), in some cases leading to permanent changes in lifestyle (Patterson et al., 2013; Bond, Hawkins, & Murphy, 2014). Disfigurement and the implications this has for patient self-esteem, body image, and mood can also produce changes in the patient-caregiver relationship, and wider family unit (Vickery et al., 2003).

Caregiver Psychological Distress

Few studies have investigated psychological adjustment in caregivers of patients with HNC. A review of the available literature suggests that these caregivers experience higher levels of anxiety compared to both the general population and the patients they are caring for, as well as significant fear of recurrence (Longacre et al., 2012). In a study involving 101 patient-caregiver dyads, Hodges and Humphris (2009) found that caregivers had higher fear of recurrence and anxiety than patients at both 3 and 6 months post-diagnosis. Similarly, partners of patients with HNC were found to have higher anxiety in a study comparing patient and partner distress post-treatment; 40% of partners had a symptom level suggestive of clinical anxiety (Vickery et al., 2003).

General distress is also evident among HNC caregivers following treatment. Ross and colleagues (2010) found that nearly 22% of caregivers reported moderate emotional distress between 6 and 24 months post-treatment, and a further 16% reported high emotional distress. Other studies suggest that caregiver distress levels may be even higher, affecting as many as 71% of those caring for patients with oesophageal cancer (Donnelly et al., 2008). Importantly, distress can be detected in spouses of patients with HNC when no distress is evident in patients themselves (Verdonck-de Leeuw et al., 2007).

The prevalence of psychological distress among HNC caregivers at diagnosis or prior to the commencement of treatment is yet to be established. Diagnosis is a particularly distressing time for patients (Haisfield-Wolfe et al., 2009), suggesting that this may also be the case for caregivers. A recent study that examined post-traumatic stress in patients and their partners within 16 weeks of HNC diagnosis found that nearly 30% of partners met criteria for estimated PTSD caseness compared to only 12% of patients (Posluszny et al., 2014).

Caregiver Distress and Outcomes

Associations between psychological distress and physical health in caregivers of patients with HNC have not been investigated. Research in caregivers of patients with other conditions suggests that mental or physical strain as a consequence of caregiving is associated with negative health effects (Pinquart & Sorensen, 2003; Vitaliano, Zhang, & Scanlan, 2003). Strained caregivers report high levels of depression and anxiety and low levels of perceived health (Schulz et al., 1997). Furthermore, a meta-analysis integrating the results of 176 studies suggests that caregiver depression has a stronger

relationship with poor physical health than objective stressors associated with caregiving (Pinquart & Sorensen, 2007). Given the high rates of distress among HNC caregivers, it is probable that these individuals are at increased risk of negative health outcomes.

Caregiver psychological distress can influence patient distress and, consequently, compromise patient treatment-related outcomes and recovery. Patient and caregiver distress symptoms were positively correlated in a meta-analysis of 21 studies involving patients with cancer and their caregivers (Hodges, Humphris, & Macfarlane, 2005). However, a study that examined psychological distress among 49 HNC patient-caregiver dyads across the course of radiotherapy discovered that an increase in distress in one member of the dyad corresponded to a decrease in distress in the other member (Badr, Gupta, Sikora, & Posner, 2014). This finding suggests that there may be different relationships between patient and caregiver distress in the context of HNC compared to other types of cancer.

Predictors of Psychological Distress

While the literature investigating factors related to psychological distress in caregivers of patients with HNC is limited, a number of variables have been identified as significant. These variables include caregiver demographic characteristics, patient physical needs, and degree of caregiver strain and burden (Blood, Simpson, Dineen, Kauffman, & Raimondi, 1994; Donnelly et al., 2008). Preliminary evidence suggests that illness perceptions and coping strategies may also be important contributors to psychological distress in HNC caregivers.

Demographic Characteristics

Demographic characteristics, including gender, age, and socioeconomic status, have been associated with psychological distress in caregivers of patients with cancer. Female caregivers tend to report higher levels of distress than male caregivers (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). Hagedoorn and colleagues (2000) found that 35% of females caring for a partner with cancer scored over the cut-off for depression on the Center for Epidemiologic Studies Depression Scale (CES-D) compared to only 12% of male caregivers. Caregivers who are younger (<50 years) have also been found to experience poor psychological health, reporting greater levels of frustration and anger than caregivers who are older (Biegel, Sales, & Schulz, 1991). Finally, caregivers of lower socioeconomic status (with limited resources and formal education) report worse psychological and physical wellbeing than those of higher socioeconomic status (Schulz & Sherwood, 2008). Currently, it

is unclear whether demographic variables are associated with psychological distress among caregivers of patients with HNC (Longacre et al., 2012).

Patient Characteristics

Several patient characteristics have a relationship with caregiver distress. Level of patient need following HNC tumour resection has been positively associated with caregiver perceptions of burden (Chen et al., 2009). Similarly, patient use of a feeding tube, lower levels of patient energy, and a disrupted life schedule have been positively related to emotional distress in spouses of patients with HNC (Verdonck-de Leeuw et al., 2007). Patient physical symptoms also contribute to caregiver distress. Increased reporting of symptoms related to the head and neck during radiotherapy corresponded with an increase in caregiver distress levels over this period (Badr et al., 2014).

Caregiver Strain

The experience of psychological distress in caregivers of patients with HNC has been directly related to the amount of strain they are under; that is, the degree to which there is severe or excessive demand on their strengths, resources, or capabilities. In a study of 94 family members of patients with oesophageal cancer, strain was positively related to both family member psychological distress and severity of mental health status (Donnelly et al., 2008). Furthermore, greater caregiver strain and schedule burden has been associated with dysregulation in caregiver diurnal cortisol rhythm over the course of HNC patient chemoradiotherapy treatment (Nightingale, Pereira, Curbow, & Carnaby, 2016a). Dysregulation was related to lower patient and caregiver quality of life. These findings are congruent with those documenting that greater perceived disruption (Blood et al., 1994) and greater time spent caregiving (Ross et al., 2010) are associated with worse HNC caregiver psychological wellbeing. Paradoxically, greater time spent caregiving per week has also been associated with less perceived disruptiveness and greater positive adaptation to caregiving (Ross et al., 2010). Previous research has found that while caregiving can have a range of negative emotional, social, and financial effects, it can also have a number of intrinsic rewards (Kim, Schulz, & Carver, 2007), such as feelings of self-worth and improved self-esteem. This may explain why positive and negative psychological outcomes can be observed simultaneously in caregivers of patients with HNC.

Illness Perceptions

While several studies have examined the relationship between illness perceptions and psychological outcomes in patients with HNC, only one study has investigated the illness perceptions of HNC caregivers. This involved 382 caregivers of patients who had been successfully treated for oesophageal cancer (Dempster et al., 2011c). Results found that caregiver illness perceptions and coping strategies explained between 35% and 49% of the variance in caregiver psychological distress (anxiety, depression, and fear of recurrence), even when controlling for confounding variables. Illness perceptions explained the greatest amount of variance in distress, with lower distress levels among caregivers who perceived fewer consequences and a good understanding of oesophageal cancer. Distress was also lower among caregivers who perceived the patient to have personal control over the disease and who attributed the cause of the cancer to external or environmental events rather than the patient's personal behaviour.

The influence of *caregiver* illness perceptions on *patient* psychological distress was also investigated by Dempster and colleagues (2011a). Data from 317 oesophageal patient-caregiver dyads found that patients were more likely to report psychological distress when their caregiver perceived the disease to have many severe consequences and believed that medical staff had little control. Caregiver illness perceptions also moderated the relationship between patient illness perceptions and patient distress. Caregiver perceptions of consequences interacted with patient perceptions to increase anxiety, while caregiver perceptions of high patient coherence interacted with low patient coherence to increase depression. Such findings suggest that caregiver illness perceptions are not only important to consider in relation to their own psychological wellbeing but also that of patients, consistent with research in a diverse range of patient-caregiver dyads (Figueiras & Weinman, 2003; Heijmans, de Ridder, & Bensing, 1999; Sterba et al., 2008; Twiddy, House, & Jones, 2012).

Although the above study provides evidence for a relationship between caregiver illness perceptions and both HNC patient and caregiver distress, there are several limitations which highlight the need for further investigations. Firstly, the study is cross-sectional and, consequently, cannot provide information as to whether caregiver perceptions (and their interaction with patient perceptions) can predict subsequent distress. Secondly, caregivers of patients at widely varying post-treatment time points were included in the study. There may be substantial variation in caregiver perceptions at different stages of the HNC trajectory, which was not examined. Furthermore, illness perceptions were

not assessed at diagnosis. By assessing perceptions at this time point it may be possible to clarify directional relationships between caregiver perceptions and future outcomes, and to determine the timeframe over which caregiver perceptions can influence patient and caregiver adjustment. Finally, the relationship between caregiver illness perceptions and other patient outcomes was not examined, such as patient HRQL (which indexes a broader range of wellbeing domains). For these reasons, additional research investigating illness perceptions in caregivers of patients with HNC is needed. Research in this area would inform the development of psychological interventions that incorporate both patients and their caregivers.

Coping

The methods HNC caregivers use to cope with the demands of their role are likely to be related to their experience of psychological distress, though only two studies have been conducted. Verdonck-de Leeuw and colleagues (2007) found that a passive coping style, characterised by pessimism, worry, high levels of introspection, and an inability to take action, was positively associated with psychological distress in 41 spouses of patients with HNC. Similarly, caregivers of patients with oesophageal cancer who reported attempting to divert their thoughts away from the disease also reported higher levels of depression and anxiety (Dempster et al., 2011c). In contrast, caregivers who reported maintaining a positive focus were found to experience fewer depression and anxiety symptoms. Interestingly, the use of interpersonal coping (seeking support from close others) among these caregivers was linked to heightened distress, particularly anxiety and fear of recurrence. This may suggest that caregivers attempted to seek support from patients, who were not in a position to respond appropriately.

Both of the studies described above utilised a cross-sectional design and investigated caregiver coping after treatment for HNC had commenced. Nevertheless, the results align with previous findings in caregivers of patients with other types of cancer. Specifically, a relationship between avoidant coping and psychological distress is well-established (Banthia et al., 2003; Kershaw, Northouse, Kritpracha, Schafenacker, & Mood, 2004; Manne & Glassman, 2000), whereby caregiver avoidant coping is predictive of poor psychological health in both caregivers *and* patients over time (Morse & Fife, 1998; Harding, Higginson, & Donaldson, 2003). Conversely, utilising engagement coping strategies has been longitudinally associated with better psychological wellbeing in a range of caregiving groups (e.g. Billings, Folkman, Acree, & Moskowitz, 2000). Determining whether these

associations can also be found over time in caregivers of patients with HNC may help to clarify whether coping is a factor that contributes to their psychological distress.

Summary

Patients with HNC are an understudied population who must contend with highly unique and distressing symptomology. In comparison to other types of cancer, HNC patient survival is low and treatment is difficult to endure. Common challenges for patients following their treatment include difficulty eating, breathing, and speaking, as well as permanent disfiguring changes in the appearance of the face, head, and/or neck. Not only does this significantly affect patient HRQL and psychological wellbeing, but also that of caregivers. Both patients and caregivers report high levels of psychological distress, including depression, anxiety, and post-traumatic stress. However, more research is needed to understand how this distress varies across the disease trajectory, particularly among HNC caregivers.

Few studies have examined factors that can predict variation in patient HRQL or patient and caregiver psychological wellbeing following HNC diagnosis and treatment. The CSM may be a useful framework for understanding variation in responding to HNC, given its utility in many other illness groups. While illness perceptions and coping strategies are associated with HRQL and psychological distress in patients with HNC, longitudinal research in this area is lacking. Relationships between illness perceptions, coping strategies, and HNC caregiver wellbeing have received even less attention. Further research to examine the predictive capacity of illness perceptions and coping at diagnosis may help to identify patients and caregivers at risk of experiencing poor outcomes, and guide the development of psychological interventions to promote recovery from HNC.

Chapter 3. Cross-sectional Relationships between Patient and Caregiver Illness Perceptions

Preface

As discussed in the preceding chapter, there is evidence to suggest that the illness perceptions of patients with HNC are associated with their health outcomes, including HRQL and psychological wellbeing. However, little attention has been paid to caregiver illness perceptions, the relationships between patient and caregiver perceptions of HNC, and whether these relationships may influence patient outcomes. Although the CSM does not specify direct relationships between caregiver perceptions and patient outcomes, the model does acknowledge that individuals construct their illness representations by drawing upon existing knowledge, including previous experiences with illness, as well as external stimuli such as social influences and information from others (Leventhal et al., 1984). Caregivers of patients with HNC are known to provide practical, emotional, and informational support for patients (Lang et al., 2013), which may influence patient perspectives of the disease, coping behaviours, and ultimately, physical and psychological health.

There is evidence that caregivers develop their own unique representations of an illness (Quinn, Jones, & Clare, 2016), and that these representations can have important implications for their emotional and behavioural responses to a patient (Barrowclough, Lobban, Hatton, & Quinn, 2001). Illness representations among caregivers are to be expected because they can experience the demands of a disease in the same manner as patients (Lewis, 1990). This is particularly so for HNC caregivers, for whom patient physical difficulties can have implications for their own communication, eating behaviours, and participation in social activities (Patterson et al., 2013; Penner, McClement, Lobchuk, & Daenink, 2012).

One aim of this thesis is to examine whether there are relationships between HNC patient and caregiver illness perceptions that can explain variation in patient adjustment and recovery. It is plausible that caregiver perceptions of HNC can moderate patients' own illness perceptions and the relationships these have with patient psychological wellbeing. Evidence to support this idea is provided by numerous studies across diverse illness groups which have found links between patient and caregiver illness perceptions and patient health. For example, in an investigation of 51 patients with

Huntington's disease and their partners, partner perceptions of a long timeline and low belief in a cure were related to lower patient vitality (Kaptein et al., 2007). Relatedly, Searle and colleagues (2007) conducted a mediation analysis to show that partner representations partially mediated the relationship between diabetes patient illness perceptions and their subsequent self-management behaviours. Similar results have been observed in the context of cancer. Spouse perceptions of a brief timeline mediated the relationship between spouse perceptions of high treatment control and improved patient HRQL 6 months later in a study of 53 patients with prostate cancer and their spouses (Wu, Mohamed, Winkel, & Diefenbach, 2013).

The degree to which patients and caregivers subscribe to the same view of illness has also been identified as important. Analyses typically reveal that similar positive perceptions of illness are related to better patient physical and psychological wellbeing (Figueiras & Weinman, 2003; Sterba et al., 2008), while conflicting perceptions are associated with higher patient distress (Heijmans et al., 1999). In fact, the impact of illness perception discrepancy on patient distress was as strong as that of baseline physical disability in a sample of 32 stroke patients and their caregivers (Twiddy et al., 2012). However, it is important that statistical investigations of patient and caregiver perceptions can identify where similarities and differences lie in order to provide a complete picture of how perceptions interact to influence patient wellbeing. Greater similarity in perceptions does not necessarily translate to positive patient outcomes. In a study investigating patients' and relatives' perceptions of eating disorders, patients who agreed with their relatives that the illness was highly distressing, chronic, and had a strong illness identity reported higher psychological distress than patients who did not (Quiles Marcos, Weinman, Terol Cantero, & Belendez Vazquez, 2009).

While previous research provides support for the role of caregiver perceptions in influencing patient responses to illness, the relationships between patient and caregiver perceptions of HNC and how these relate to patient HRQL are yet to be explored. Only one study has examined interactions between HNC patient and caregiver illness perceptions (Dempster et al., 2011a). This cross-sectional study showed that caregiver perceptions interacted with those of patients to impact patient distress (depression and anxiety symptoms) approximately 4 years post-diagnosis. Given that such associations can be observed late in the disease trajectory (after the physical effects and psychological impact of HNC have markedly diminished), it is likely that they can also be identified at earlier time points. Furthermore, associations between patient and caregiver illness perceptions may relate to a broader range of wellbeing domains than has previously been investigated.

The following paper presents the first analyses of baseline data from Study 1 of this thesis, a prospective study that examined psychological variables in patients with HNC and their caregivers at diagnosis and again 6 months later. An investigation of the relationships between patient and caregiver illness perceptions at diagnosis and how these are cross-sectionally related to patient HRQL (including physical, social, emotional, functional, and head and neck specific wellbeing) was performed.

Citation

Richardson, A. E., Morton, R., & Broadbent, E. (2015). Caregivers' illness perceptions contribute to quality of life in head and neck cancer patients at diagnosis. *Journal of Psychosocial Oncology*, 33, 414-432. doi: 10.1080/07347332.2015.1046011



Abstract

This study investigated the contribution of patient and caregiver illness perceptions to the quality of life of patients with HNC. Ninety-eight patients and their caregivers ($n = 80$) completed questionnaires at diagnosis. Caregivers' illness perceptions were significantly more negative than patients with respect to consequences, timeline, treatment, concern, and the emotional impact of HNC. The interaction between several patient and caregiver illness perceptions explained additional variance in patient quality of life, above and beyond patients' own illness perceptions. These findings suggest that caregivers should be included in psychological interventions to improve HNC patient quality of life.

Background

Head and neck cancer treatment is associated with a range of side effects that negatively impact basic functions, such as speaking, breathing, swallowing and eating (Abendstein et al., 2005). Furthermore, treatment for HNC can result in significant changes in appearance, including disfigurement of the head and neck region (List & Bilir, 2004). This can leave patients vulnerable to psychological distress, relationship difficulties, and social isolation (Singer et al., 2012). Patients' HRQL is most negatively impacted during and immediately after treatment (Howren et al., 2013), after which it gradually improves (Morton & Izzard, 2003). However, there is significant variation in this trajectory (Ronis et al., 2008), with some patients regaining normal function soon after treatment and others continuing to experience impaired HRQL for a number of years (Funk et al., 2012). It is important to investigate factors that may explain this variation.

While disease-specific factors (including tumour site and stage, treatment modality, and treatment associated complications) contribute significantly to HRQL (de Graeff et al., 2000b; Hammerlid et al., 2001), psychological factors have also been identified (Howren et al., 2013). In particular, the way in which patients perceive and cope with HNC can influence their HRQL (Llewellyn et al., 2007a; Scharloo et al., 2005) and psychological wellbeing (Dempster et al., 2011b; Llewellyn et al., 2007b). This is explained by the CSM (Leventhal et al., 1980), which proposes that patients hold cognitive and emotional representations of their illness that guide the ways in which they cope. Coping behaviours then influence subsequent health outcomes. Patients appraise the effectiveness of their coping behaviours which can lead to the modification of illness representations. Cognitive representations have been found to centre around five key perceptions: the identity of the illness (its label and symptoms); its timeline (how long it will last); causes of the illness; its consequences; and how it may be cured or controlled (Leventhal et al., 1980). More recently, patients' coherence (i.e. their understanding) and their perceived emotional impact of the illness have been added to the CSM (Moss-Morris et al., 2001).

Illness perceptions have associations with coping behaviours, physical recovery, and psychological wellbeing, in a diverse range of patient groups (Hagger & Orbell, 2003), including patients with HNC. Perceiving HNC to have few consequences has predicted better HNC patient functioning 2 years later (Scharloo et al., 2010), and perceiving a long illness duration has predicted depression 6-8 months after treatment (Llewellyn et al., 2007b). Furthermore, negative perceptions of

HNC have been associated with the use of maladaptive coping strategies, such as avoidance, substance use, and behavioural disengagement (Llewellyn et al., 2007a). Patients who adopt these coping strategies are at increased risk of psychological distress and poor HRQL (Aarstad et al., 2012; Derks et al., 2004; Elani & Allison, 2011).

While illness perceptions and coping strategies have been associated with outcomes in patients with HNC, research investigating these variables in their caregivers has been limited. This is despite evidence that caregivers of HNC patients experience worse psychological health and higher levels of anxiety than patients (Longacre et al., 2012). In other types of cancer, research has shown that when caregivers perceive the cancer to be serious they are more likely to be anxious or depressed (Compas et al., 1994), report more illness-related demands and concerns (Lewis, Woods, Hough, & Bensley, 1989), feel more uncertain or hopeless (Keitel, Cramer, & Zevon, 1990; Northouse et al., 2002), and consider treatments to be stressful (Keitel et al., 1990). There is also evidence to suggest that caregivers hold perceptions that are more negative than those of patients (Kaptein et al., 2007; Karademas, Zarogiannos, & Karamvakalis, 2010; Twiddy et al., 2012). The illness perceptions of caregivers can significantly affect patient illness perceptions, coping, psychological wellbeing, and physical functioning (Figueiras & Weinman, 2003; Heijmans et al., 1999; Sterba et al., 2008).

Caregiver illness perceptions and coping have been associated with both caregiver and patient distress in studies of individuals affected by oesophageal cancer (Dempster et al., 2011a; Dempster et al., 2011c). Indeed, significant interactions between caregiver and patient illness perceptions have been found, indicating that some caregiver perceptions may moderate relationships between patient perceptions and patient distress. However, results may not generalise to all HNC patients, and the effects of caregiver perceptions on patient HRQL are yet to be investigated.

This study aimed to investigate illness perceptions in HNC patients and their caregivers (patient-caregiver dyads) at diagnosis, and to determine relationships with patient HRQL. Based on the results of previous studies, we hypothesised that: (1) caregiver illness perceptions would be more negative than patient illness perceptions; (2) patients' illness perceptions would predict HRQL over and above medical and demographic variables; and (3) interactions between the illness perceptions of patients and their caregivers would contribute to patient HRQL over and above patient medical and demographic variables and patient illness perceptions.

Methods

Participants

Participants were a sample of 98 HNC patients recruited consecutively from a head and neck outpatient clinic at Auckland City Hospital, New Zealand, between February and December 2013. Inclusion criteria were a diagnosis of primary epithelial head and neck cancer (carcinoma in the pharynx, larynx, oral cavity, sinonasal cavity), or an advanced (metastatic) skin cancer in the head and neck region, up to 3 weeks prior to clinic attendance. Patients' caregivers (family members or support persons in attendance at the clinic) were invited to participate, resulting in 80 patient-caregiver dyads. Exclusion criteria were conditions that would interfere with participation (including cognitive impairments, significant physical disabilities, or severe psychiatric conditions), insufficient understanding of English, or a palliative care treatment plan.

Power Analysis

Caregivers' illness perceptions contributed to oesophageal cancer patient distress, representative of a medium effect size $f^2 = .186$ (Dempster et al., 2011a). Setting power at .80 and alpha at .05, G-power software (Faul, Erdfelder, Lang, & Buchner, 2007) indicated that a sample of 70 patient-caregiver dyads would be needed to detect this effect (when using four predictors in a regression model).

Procedure

After obtaining written informed consent, patients and their caregivers completed measures of illness perceptions and coping. Patients also completed a HRQL measure. Diagnosis, stage of cancer, and treatment information was retrieved from medical records. Ethics approval was obtained from the University of Auckland Human Participants Ethics Committee and the Auckland District Health Board Research Review Committee.

Measures

Brief Illness Perception Questionnaire (B-IPQ)

The Brief-IPQ is a nine-item scale designed to assess cognitive and emotional representations of illness (Broadbent, Petrie, Main, & Weinman, 2006). Six of the items assess cognitive illness representations (consequences, timeline, personal control, treatment control, causes, and identity), two items assess emotional representations (concern and emotions), and one item assesses illness coherence. Items are rated on a 10-point Likert scale, with higher scores representing stronger beliefs. The Brief-IPQ has good test-retest reliability, convergent validity, and predictive validity (Broadbent et al., 2006).

Caregiver Brief Illness Perception Questionnaire

The Brief-IPQ was re-worded to assess caregivers' perceptions of patients' illness, a technique that has been used in previous studies (Broadbent, Ellis, Thomas, Gamble, & Petrie, 2009a). For two items (consequences and control), caregivers rate their perceptions of the patient's illness as well as their perceptions regarding their own life in separate questions. For example, 'How much control do you feel you have over your family member's illness?' and 'How much control do you think your family member has over his/her illness?'

Brief COPE

The Brief COPE is a self-report scale consisting of 28 items that assess different ways of coping (Carver, 1997). Responses are made on a 4-point Likert scale, with ratings indexing the extent to which different behaviours have been engaged in. Fourteen subscales assess conceptually different coping behaviours. These subscales have adequate internal consistency (Carver, 1997). The Brief COPE has been administered in diverse samples, in several different countries (e.g. Kapsou, Panayiotou, Kokkinos, & Demetriou, 2010).

Functional Assessment of Cancer Therapy – Head and Neck (FACT-H&N)

The main outcome was HRQL as assessed by the FACT-H&N, a multidimensional self-report scale (Cella et al., 1993). The measure consists of 27 items, including five components that assess physical, emotional, social, functional, and head and neck specific wellbeing. The FACT-H&N has been

validated in patients with HNC (List et al., 1996). The subscales demonstrated good reliability in the present study, with Cronbach's alpha coefficients of .89, .80, .81, .85, and .77 for the physical, social, emotional, functional, and head and neck specific subscales respectively, and .74 for the total scale.

Analysis

Data were analysed using SPSS version 21. Independent t-tests were performed to determine the impact of demographic and medical characteristics (gender, tumour stage, cancer type) on patient HRQL. Pearson correlation coefficients and hierarchical multiple regression analysis were used to investigate the relationships between patient illness perceptions, coping, and HRQL. For these analyses, all 98 patients were used (including patients without a caregiver) to increase power and generalisability. Demographic and medical variables (age and tumour stage) were entered into the regression model in step 1 to control for their potential influence. In step 2, only illness perceptions and coping strategies that were found to significantly correlate with HRQL were entered, in order to limit the number of variables in the model and to avoid multicollinearity.

Using the data from the 80 patient-caregiver dyads, paired t-tests were conducted to investigate differences in illness perceptions and coping between patients and caregivers. In addition, hierarchical multiple regression analyses were conducted to investigate the influence of interactions between patient and caregiver illness perceptions on patient HRQL. Similar to Dempster and colleagues (2011a), separate analyses were performed to look at the contribution of each individual patient and caregiver illness perception, and the interaction between the two, after first controlling for the influence of patient tumour stage. Simple slope analyses were used to interpret significant interaction effects. This is an effective method for investigating how the interdependence of patient and caregiver illness perceptions contributes to patient outcome scores. For all tests, a two-sided *p*-value less than .05 was considered statistically significant. Missing data were addressed using the method of pairwise deletion. Analyses were repeated when excluding patients with skin cancer in order to determine whether this made a difference to the results.

Results

Table 1 presents participant characteristics, including the medical and demographic characteristics of HNC patients and caregivers. No significant difference was observed between patients with HNC and patients with metastatic skin cancer in the head and neck region with respect to

total HRQL ($t(89) = -1.31, p = .19$). However, there was a significant difference in total HRQL between patients with a T1-T2 tumour ($M = 120.10, SD = 18.84$) and patients with a T3-T4 tumour ($M = 109.75, SD = 22.16; t(89) = 2.29, p = .02$).

Table 1. Demographic and medical characteristics of patients and caregivers at diagnosis

	Patients ($n = 98$)	Caregivers ($n = 80$)
Gender		
Male	74 (76%)	16 (16%)
Female	24 (24%)	64 (65)
Ethnicity		
New Zealand European	71 (73%)	56 (70%)
Māori	12 (12%)	9 (11%)
Chinese	6 (6%)	2 (3%)
Indian	4 (4%)	5 (6%)
Other	5 (5%)	8 (10%)
Marital Status		
Single	11 (11%)	5 (6%)
Married	69 (71%)	67 (84%)
Divorced	9 (9%)	7 (9%)
Widowed	9 (9%)	1 (1%)
Smoking Status		
Yes	19 (19%)	6 (7%)
No	79 (81%)	74 (93%)
Cancer Type		
Oral cavity, pharynx, larynx	81 (83%)	
Metastatic skin cancer	14 (14%)	
Sinonasal cancer	3 (3%)	
Tumour Stage		
T1-T2	69 (70%)	
T3-T4	29 (30%)	
Relationship to Patient		
Spouse/Partner		44 (55%)
Child (son or daughter)		19 (24%)
Grandchild		2 (2.5%)
Sibling		7 (9%)
In-law		2 (2.5%)
Friend		5 (6%)
Formal carer		1 (1%)

Associations between Patient Illness Perceptions, Coping, and HRQL

The regression model specified in Table 2 explained 59% of the variance in overall patient HRQL [adjusted $R^2 = 55%$; $F(6, 73) = 17.37, p < .001$]. Tumour stage and age explained 7% of the variance. Illness perceptions (identity and consequences) explained 39% of the variance over and above these variables. Coping strategies (substance use and behavioural disengagement) contributed an additional 12%.

Table 2. Regression analysis with total patient HRQL as the outcome variable

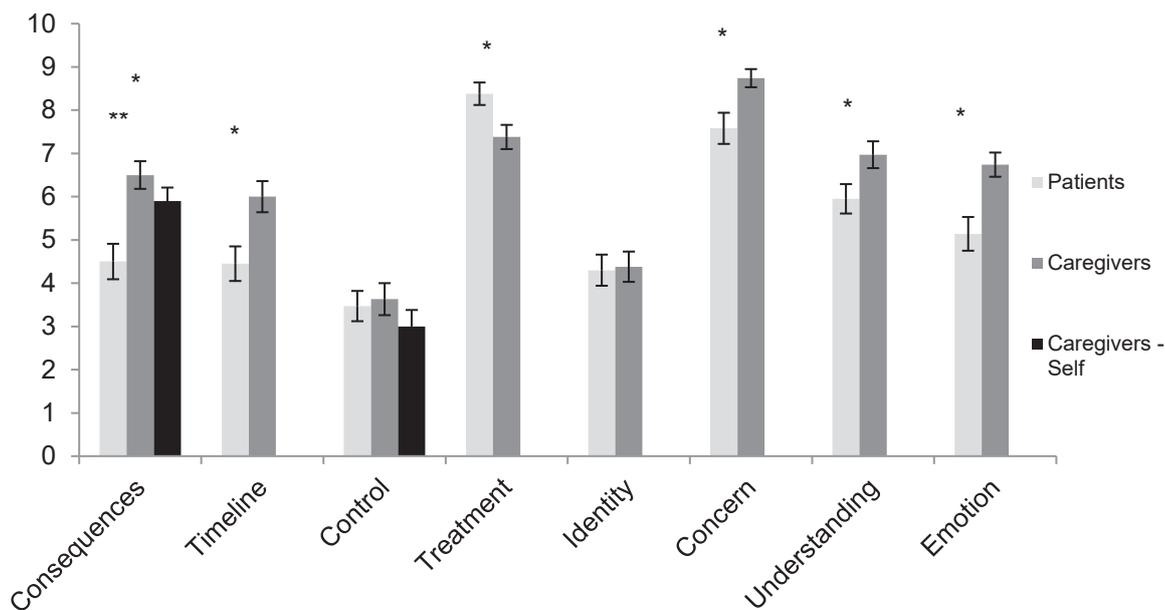
	b	β	t
(Constant)	154.57		20.14**
Tumour stage	-1.74	-.04	-0.51
Age	-0.02	-.02	-0.19
B-IPQ Consequences	-1.75	-.28	-2.59*
B-IPQ Identity	-2.11	-.32	-3.12*
Substance Use	-4.13	-.30	-3.79**
Disengagement	-3.51	-.20	-2.32*

Note. * $p < .05$, ** $p < .001$; B-IPQ = Brief Illness Perception Questionnaire

Differences in Illness Perceptions between HNC Patients and Caregivers

Caregivers perceived significantly greater consequences of HNC than did patients (for both the patient ($t(71) = -3.98, p < .001, d = .63$) and themselves ($t(71) = -2.89, p = .005, d = .47$)). They also thought that the disease would last longer ($t(61) = -3.66, p < .001, d = .52$), reported a greater emotional impact ($t(72) = -3.31, p < .001, d = .55$), had greater concern ($t(72) = -3.00, p = .004, d = .46$), and higher coherence than patients ($t(72) = -2.45, p = .017, d = .37$). There were no differences between patients and caregivers in identity or in perceived control, with low control perceptions among both. However, patients perceived treatment to be more helpful than caregivers ($t(67) = 3.10, p = .003, d = .45$) (Figure 2).

Figure 2. Differences in illness perceptions between patients and caregivers



Note. * $p < .05$, ** $p < .001$. Bars indicate mean values on each B-IPQ item and error bars represent standard errors. For perceptions of consequences and control, dark grey bars indicate caregivers' perceptions of the illness for the patient, and black bars indicate caregivers' perceptions of the illness for their own life.

Interactions between HNC Patient and Caregiver Illness Perceptions and Patient HRQL

Coherence

Patient coherence, caregiver coherence, and their interaction explained 13% of the variance in patient *total* HRQL. The interaction explained 5% of this variance, making a statistically significant unique contribution. A simple slope analysis suggested that when patients and caregivers had similar coherence perceptions (i.e. both high or both low) patients reported higher total HRQL compared to when they had dissimilar coherence perceptions (Figure 3). Interaction terms also explained an additional 20% of the variance in *functional* HRQL and 45% of the variance in *social* HRQL (Table 3).

Figure 3. Simple slope analysis demonstrating interaction between patient and caregiver coherence and patient total HRQL

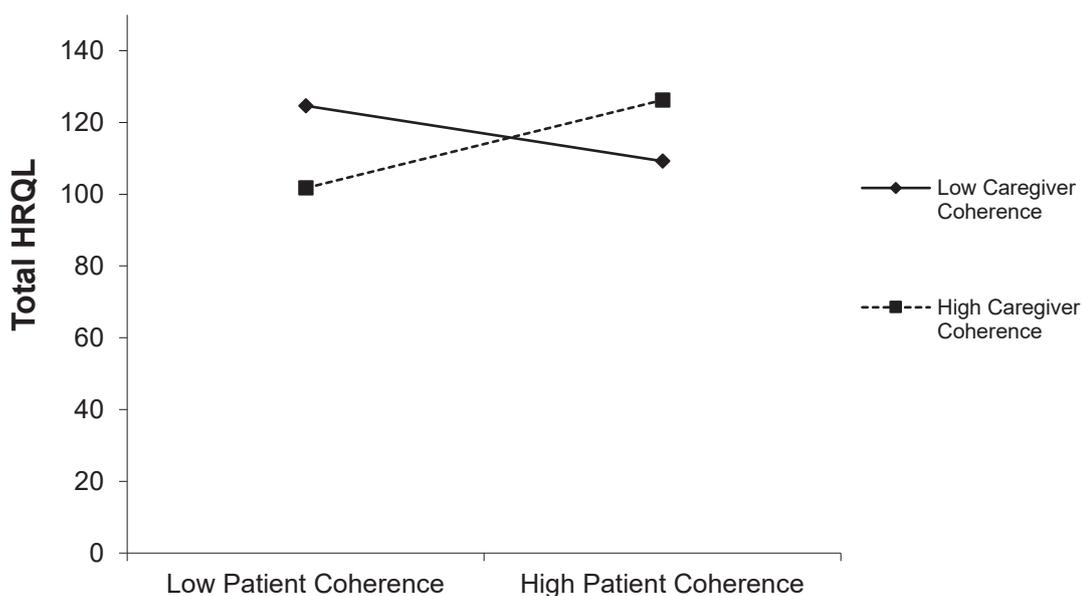


Table 3. The contribution of interactions between patient and caregiver coherence perceptions to patient HRQL

	b	β	t
TOTAL HRQL			
(Constant)	155.91		7.59**
Tumour Stage	-7.30	-.16	-1.39
Patient Perception	-6.10	-.93	-1.66
Caregiver Perception	-6.08	-.83	-2.06*
Interaction (patient x caregiver)	0.99	1.43	1.95*
FUNCTIONAL HRQL			
(Constant)	42.54		7.90**
Tumour Stage	-0.82	-.06	-0.59
Patient Perception	-3.83	-2.02	-3.96**
Caregiver Perception	-3.51	-1.66	-4.52**
Interaction (patient x caregiver)	0.58	2.92	4.35**
SOCIAL HRQL			
(Constant)	51.29		14.14**
Tumour Stage	1.68	.15	1.80
Patient Perception	-4.87	-2.86	-7.49**
Caregiver Perception	-4.69	-2.46	-8.97**
Interaction (patient x caregiver)	0.77	4.33	8.62**

Note. * $p < .05$, ** $p < .001$; Total HRQL Model $R^2 = 13\%$ [adjusted $R^2 = 7.5\%$; $F(4,68) = 2.54$, $p = .055$]; Functional HRQL Model $R^2 = 27\%$ [adjusted $R^2 = 23\%$; $F(4,68) = 6.38$, $p < .001$]; Social HRQL Model $R^2 = 59\%$ [adjusted $R^2 = 57\%$; $F(4,68) = 24.74$, $p < .001$]

Timeline

Patient timeline perceptions, caregiver timeline perceptions, and their interaction explained 16% of the variance in *social* HRQL. The interaction term explained 7% of this variance, making a statistically significant unique contribution (Table 4). A simple slope analysis demonstrated that patient *social* HRQL was highest when both patients and caregivers had low timeline perceptions. However, *social* HRQL was lowest when caregivers had long timeline perceptions, particularly if patients' own timeline perceptions were short.

The interaction between patient and caregiver timeline perceptions also explained an additional 8% of the variance in *functional* HRQL, above and beyond patients' and caregivers' own individual timeline perceptions (Table 4). *Functional* HRQL was highest when patients and caregivers both had short timeline perceptions and lowest when patients and caregivers both had long timeline perceptions.

Table 4. The contribution of interactions between patient and caregiver timeline perceptions to patient HRQL

	b	β	t
SOCIAL HRQL			
(Constant)	29.10		11.76**
Tumour Stage	-0.61	-.05	-0.41
Patient Perception	-0.94	-.53	-1.48
Caregiver Perception	-1.23	-.66	-3.10*
Interaction (patient x caregiver)	0.18	.97	2.19*
FUNCTIONAL HRQL			
(Constant)	27.22		9.81**
Tumour Stage	-1.93	-.15	-1.17
Patient Perception	-1.83	-.93	-2.60*
Caregiver Perception	-0.93	-.45	-2.10*
Interaction (patient x caregiver)	0.21	1.02	2.30*

Note. * $p < .05$, ** $p < .001$; *Social* HRQL Model $R^2 = 16\%$ [adjusted $R^2 = 10\%$; $F(4,57) = 2.65$, $p = .042$]; *Functional* HRQL Model $R^2 = 15\%$ [adjusted $R^2 = 9\%$; $F(4,57) = 2.59$, $p = .046$]

Control

Patient perceptions of control, caregiver perceptions of the patient's control, and the interaction between these perceptions explained 22% of the variance in *social* HRQL. The interaction contributed 12% of this variance, and also contributed to 5% of the variance in *functional* HRQL (Table 5). *Social*

HRQL was highest when patients and caregivers both had low perceptions of control and lowest when patients had low control perceptions but their caregivers had high control perceptions. Conversely, *functional* HRQL was highest when patients and caregivers reported high control perceptions and lowest when patients had low perceptions of control and caregivers perceived patient control to be high.

Table 5. The contribution of interactions between patient and caregiver control perceptions to patient HRQL

	b	β	t
SOCIAL HRQL			
(Constant)	25.93		17.72**
Tumour Stage	-1.04	-.08	-0.75
Patient Perception	-0.31	-.18	-0.91
Caregiver Perception	-1.29	-.76	-3.86**
Interaction (patient x caregiver)	0.20	.88	3.16*
FUNCTIONAL HRQL			
(Constant)	21.17		12.56**
Tumour Stage	-2.44	-.19	-1.70
Patient Perception	0.15	.08	0.39
Caregiver Perception	-0.93	-.50	-2.49*
Interaction (patient x caregiver)	0.14	.56	2.01*

Note. * $p < .05$, ** $p < .001$; *Social* HRQL Model $R^2 = 22\%$ [adjusted $R^2 = 18\%$; $F(4,65) = 4.69$, $p = .002$]; *Functional* HRQL Model $R^2 = 21\%$ [adjusted $R^2 = 16\%$; $F(4,65) = 4.38$, $p = .003$]

Treatment Control

Patient treatment control perceptions, caregiver treatment control perceptions, and the interaction between them explained 15% of the variance in *functional* HRQL [adjusted $R^2 = 10\%$; $F(4,62) = 2.83$, $p = .032$]. The interaction term explained 8% of this variance, above and beyond patients' and caregivers' individual treatment control perceptions ($\beta = 1.36$, $t = 2.39$, $p = .020$). When HNC patients and caregivers both perceived treatment to be helpful, *functional* HRQL was highest. *Functional* HRQL was reduced when caregivers perceived treatment to be less helpful than patients.

Identity

Patient identity perceptions, caregiver identity perceptions, and the interaction between these perceptions explained 31% of the variance in patient *physical* HRQL [adjusted $R^2 = 27\%$; $F(4,64) = 7.28$, $p < .001$]. The interaction term explained 5% of this variance, making a statistically significant

unique contribution ($\beta = -.60, t = -2.17, p = .034$). As patients' perceptions of illness identity increased their *physical* HRQL decreased, and this effect was particularly pronounced when caregivers also had high identity perceptions.

Emotion

Patient perceptions of emotional impact, caregiver perceptions of emotional impact, and the interaction between these perceptions explained 53% of the variance in *emotional* HRQL [adjusted $R^2 = 50\%$; $F(4,68) = 19.04, p < .001$]. The interaction term explained 4% of this variance, making a statistically significant unique contribution ($\beta = -.70, t = -2.42, p = .018$). As patients' perceptions of the emotional impact increased their *emotional* HRQL decreased, and this effect was most notable when caregivers also reported a large emotional impact.

Concern

Patient concern perceptions, caregiver concern perceptions, and the interaction between these perceptions explained 20% of the variance in patient *social* HRQL and 29% of the variance in patient *head and neck specific* HRQL. The interaction term explained 17% and 14% of this variance, respectively (Table 6). When patients and their caregivers both had high concern perceptions, patients reported poorer *social* HRQL compared to when patients had high concern perceptions and their caregivers had low concern perceptions. When patients and caregivers both had low levels of concern, *head and neck specific* HRQL was highest.

Table 6. The contribution of interactions between patient and caregiver concern perceptions to patient HRQL

	b	β	t
SOCIAL HRQL			
(Constant)	-2.53		-0.31
Tumour Stage	-1.33	-.12	-1.04
Patient Perception	4.44	2.62	3.76**
Caregiver Perception	2.91	.99	3.14*
Interaction (patient x caregiver)	-0.49	-3.02	-3.82**
HEAD AND NECK HRQL			
(Constant)	80.03		7.15**
Tumour Stage	-3.07	-.18	-1.76
Patient Perception	-6.39	-2.60	-3.97**
Caregiver Perception	-4.29	-1.01	-3.40**
Interaction (patient x caregiver)	0.63	2.68	3.60**

Note. * $p < .05$, ** $p < .001$; Social HRQL Model $R^2 = 20\%$ [adjusted $R^2 = 15\%$; $F(4,68) = 4.13$, $p = .005$]; Head and Neck Specific HRQL Model $R^2 = 29\%$ [adjusted $R^2 = 25\%$; $F(4,68) = 6.91$, $p < .001$]

Repeating these regressions when excluding patients with skin cancer made no difference to the pattern of results, except in one case – treatment control. The overall model was not significant [adjusted $R^2 = 4\%$; $F(4,52) = 1.57$, $p > .05$], and the interaction term no longer made a unique statistically significant contribution ($\beta = 1.16$, $t = 1.89$, $p > .05$).

Discussion

This is the first study to show that the illness perceptions of those caring for patients with HNC can contribute to patient HRQL at diagnosis. The results showed that patient and caregiver perceptions of HNC interact to influence not only global HRQL, but also functional, physical, social, emotional, and head and neck specific wellbeing. These findings highlight the importance of establishing methods that increase the degree to which patient and caregiver perceptions align, in an effort to maximise the physical and psychological functioning of HNC patients.

On the whole, interactions between patient and caregiver illness perceptions were found to be related to relevant HRQL domains. For example, perceptions of many symptoms interacted to decrease physical HRQL, while perceptions of emotional impact interacted to decrease emotional HRQL. In both cases, HRQL was lower when patients reported negative perceptions, and these effects were particularly pronounced when caregivers also had negative perceptions. The alignment of

negative perceptions between patients with HNC and their caregivers may serve as a form of validation to patients, reinforcing the experience of low HRQL.

Some interactions between patient and caregiver illness perceptions influenced a number of different aspects of HRQL. In particular, illness coherence perceptions consistently interacted to affect not only overall HRQL, but also functional and social HRQL. Patients reported better HRQL when they and their caregivers had concordant coherence (i.e. both high/both low) compared to when they had dissimilar coherence. Similar levels of coherence may be important because they increase the extent to which patients feel united with their caregivers. Conversely, patients and caregivers with a dissimilar understanding of HNC may be more likely to experience conflict or disagreement, particularly regarding what is best for the patient.

Caregiver concern interacted with patient concern to influence patient HRQL. This outcome was lowest when patients had high levels of concern and caregivers had low levels of concern. A possible explanation for this is that patients interpret low caregiver concern as minimising the seriousness of their illness. Similar results were found regarding the interaction between patient and caregiver timeline perceptions. For both functional and social domains, HRQL was best when both patients and their caregivers perceived a short timeline, and worst when patients had short timeline perceptions but their caregivers had long timeline perceptions. Importantly, the interactions between patient and caregiver illness perceptions made a clinically significant difference to patient HRQL – that is, a difference in FACT-H&N scores of at least 6 units (Ringash, O'Sullivan, Bezjak, & Redelmeier, 2007).

The results support previous research in oesophageal cancer, which found that patient and caregiver perceptions of consequences and coherence interacted to influence patient anxiety and depression, respectively (Dempster et al., 2011a). Caregivers' illness perceptions have also been shown to influence patient quality of life among individuals with Huntington's disease (Kaptein et al., 2007), chronic fatigue syndrome, and Addison's disease (Heijmans et al., 1999). Consistent with our findings, the most negative impact is observed for patients whose spouses' illness perceptions communicate a minimisation of the illness. However, not all studies have found that caregivers' illness perceptions relate to patient outcomes (Karademas et al., 2010; Richards et al., 2004). Mixed results may in part be attributable to variations in analysis. Caregivers' perceptions appear to impact patient

outcomes in a more complex way than simple examinations of dissimilarity can reveal (Dempster et al., 2011a).

These findings have clear implications for the design and development of psychological interventions that aim to improve HNC patient HRQL at diagnosis. Specifically, interventions need to involve both patients and caregivers, and target their individual perceptions about the disease. An effort should be made to ensure that both patients and caregivers hold accurate perceptions regarding what can be expected from HNC and its treatment (including the consequences, duration, identity, and emotional impact), and that these perceptions are broadly in line. The results of the present study suggest that the degree of match between HNC patient and caregiver perceptions is particularly important with respect to coherence, concern, and timeline, where differences may lead to patients feeling that caregivers are minimising the seriousness of the situation. An effective way to address illness perceptions in a psychological intervention is to provide highly individualised information that can improve understanding about a condition (Wearden & Peters, 2008).

Addressing the perceptions of caregivers is particularly important because they perceived a greater emotional impact, worse consequences, a longer timeline, and thought that treatment was less likely to be helpful than patients. These results are similar to those documented in other illness groups (Heijmans et al., 1999; Kaptein et al., 2007; Karademas et al., 2010). Dempster and colleagues (2011a) reported that caregivers perceived more negative consequences of oesophageal cancer than patients. One reason for which patients' perceptions of illness are more positive than caregivers' may be preservation of self-concept. This phenomenon is illustrated by research showing that when individuals are told they have an illness they perceive the illness as less serious than individuals told they do not have the illness (Jemmott, Ditto, & Croyle, 1986). Caregivers' perceptions may also be more negative because they are concerned about how they will cope with what lies ahead. Research suggests that greater clinical support in the form of practical assistance and information is required for those caring for patients with HNC (Ross et al., 2010).

While the effectiveness of psychological interventions for caregivers of patients with HNC is yet to be investigated, there is some evidence to support their use in patients. For example, an illness perception based intervention reduced patient fear of recurrence and anxious preoccupation after the completion of treatment for oral and oropharyngeal cancer (Humphris & Rogers, 2012). However, more

research is needed to investigate the impact of psychological interventions in this group (Semple et al., 2013), particularly during treatment when HRQL is most impaired.

The results suggest that psychological interventions should also address coping strategies. In this study, both illness perceptions and coping were associated with HNC patient HRQL, which is consistent with the CSM (Leventhal et al., 1980). Patients who perceived worse consequences and a strong illness identity had lower HRQL, in line with previous findings (Llewellyn et al., 2007a; Scharloo et al., 2005). Furthermore, patients who used behavioural disengagement and substances to cope with HNC had lower HRQL. The use of disengagement coping strategies (including substance use) has consistently been associated with worse physical and psychological health in this patient group (Aarstad et al., 2012; Elani & Allison, 2011; Johansson et al., 2011; List et al., 2002). Interventions could discourage the use of such strategies by providing alternatives, such as engagement-focused techniques.

This study is limited by its cross-sectional nature and future research should investigate these effects longitudinally. Nevertheless, the results suggest that the illness perceptions of caregivers can have a significant impact on numerous quality of life domains in patients with HNC. More work is needed to establish the effectiveness of psychological interventions that target the illness perceptions of both patients and their caregivers.

Chapter 4. Longitudinal Relationships between Patient and Caregiver Illness Perceptions

Preface

The previous paper identified that HNC patient and caregiver illness perceptions interacted to influence various aspects of patient wellbeing at time of diagnosis. However, the cross-sectional nature of this investigation prevented conclusions regarding relationships between patient and caregiver illness perceptions over time, and whether these relationships continue to be related to patient outcomes at later stages in the HNC trajectory. A primary aim of this thesis is to identify whether the illness perceptions of patients and caregivers are not only related to patient adjustment, but whether or not these perceptions can predict long-term adaptation to the disease. Therefore, longitudinal investigation of HNC patient and caregiver illness perceptions is necessary in order to determine the temporal ordering of illness perception processes and their subsequent impact on patient HRQL.

Although several studies have examined caregiver illness perceptions as predictors of patient outcomes, others have considered whether the *discrepancy* between patient and caregiver perceptions is important. A benefit of investigating the role of differences in illness perceptions is that this approach acknowledges the interdependence of perceptions within a dyad or family unit. It is well-recognised that the social environment influences self-regulation, including the patient's individual illness perceptions and coping behaviours (Leventhal, Leventhal, & Contrada, 1998). Differences in perceptions between patients and their caregivers may lead to the caregiver providing inadequate or inappropriate support, negatively impacting intimacy, as well as patient physical and psychological health.

The degree of similarity between HNC patient and caregiver illness perceptions, and the relationship between this similarity and patient outcomes, is yet to be explored over time (Sterba et al., 2016). However, longitudinal research has been conducted in patients and caregivers affected by other illnesses. This research suggests that the absence of discrepancies between patient and caregiver illness perceptions is associated with better future physical and psychological functioning and lower levels of distress among patients (Figueiras & Weinman, 2003; Sterba et al., 2008). Conversely, discrepancies in patient and caregiver illness perceptions have been found to adversely impact patient

wellbeing (Twiddy et al., 2012), particularly when caregivers underestimate the impact of an illness or disease (Sterba et al., 2008). Kuipers and colleagues (2007) showed that discrepancy in patient and caregiver perceptions of consequences was related to greater depression and anxiety and reduced self-esteem among 82 individuals with psychosis and their caregivers.

The relationship between illness perception discrepancy and poor outcomes has also been documented in patients with cancer and their caregivers. When husbands of women with breast cancer had discrepant perceptions of their wives' adjustment, this mediated the relationship between wives' use of avoidant coping strategies and their degree of mood disturbance in a study of 45 patient-caregiver dyads (Romero, Lindsay, Dalton, Nelson, & Friedman, 2008). However, research is yet to examine the influence of discrepancies regarding illness-specific cognitions among couples coping with cancer and no studies have adopted a longitudinal design. It is important to recognise that the influence of illness perception discrepancy is likely to be variable across different illnesses. In a cross-sectional comparison of perceptions among patients with Addison's disease (AD) and patients with chronic fatigue syndrome (CFS) and their spouses, dissimilarity in timeline beliefs was associated with worse physical, social, and psychological adjustment for AD patients, while dissimilarity in these beliefs was related to better adjustment scores among patients with CFS (Heijmans et al., 1999).

Discrepancies in the illness perceptions of patients with HNC and their caregivers at diagnosis were noted in the previous chapter, with caregivers more negative than patients with respect to the consequences, timeline, treatment, concern, and emotional impact of the disease (Richardson et al., 2015a). These discrepancies have also been documented among HNC patients and caregivers who are several years post-treatment (Dempster et al., 2011a), and are consistent with the broader literature documenting greater negativity in the illness perceptions of caregivers (Kaptein et al., 2007; Karademas et al., 2010; Twiddy et al., 2012). Discrepancies in illness perceptions are evident even when patients and their caregivers report being happy with their relationship (Heijmans et al., 1999).

Given that research in other patient groups suggests that differences in patient and caregiver illness perceptions can negatively influence patient outcomes, investigations are needed to determine whether the discrepancies evident between HNC patient and caregiver perceptions at diagnosis can predict patient HRQL following treatment. This would help to improve understanding of the factors that explain variation in this important outcome. The results may highlight a potential opportunity for psychological interventions that encourage similar positive and accurate perceptions of HNC among

patients and their caregivers. The paper presented below addresses the limitations associated with the cross-sectional analyses described in the previous chapter by examining the way in which dyadic beliefs about HNC are associated with patient HRQL over time.

Citation

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Abstract

Objective: This study investigated changes in illness perceptions from diagnosis to 6 months later in patients with HNC and their caregivers. The study also examined whether discrepancy in patient and caregiver perceptions at diagnosis could predict patient HRQL at 6 months.

Design: Forty-two patient-caregiver dyads completed the Brief Illness Perception Questionnaire (Brief-IPQ) at diagnosis and again 6 months later. Patients also completed a HRQL questionnaire at both time points. Analyses were performed using the APIM.

Main Outcome Measure: Total patient HRQL assessed by the Functional Assessment of Cancer Therapy (FACT-H&N).

Results: Perceptions of emotional impact and illness concern reduced over time in patients and caregivers. Perceptions of treatment control and identity increased in caregivers only. After controlling for the effects of baseline HRQL, and the individual contribution of patient and caregiver illness perceptions, greater discrepancy in perceptions of timeline, personal control, and illness identity among dyads at diagnosis predicted lower patient HRQL at 6 month follow-up.

Conclusion: Patients' and their caregivers' perceptions of HNC are dynamic over time. Greater discrepancy between patients' and caregivers' illness perceptions at diagnosis predict poorer subsequent patient HRQL.

Background

Cancers of the head and neck include those that develop in or around the oral cavity, pharynx, larynx, paranasal sinuses, nasal cavity, and salivary glands. Consequently, HNC often compromises the integrity of the head and neck region, an area of the body that is highly visible to others (Hagedoorn & Molleman, 2006). Patients with HNC must face challenges often not experienced by those dealing with other types of cancer, including long-term changes in the ability to breathe, speak, and swallow, significant disfigurement, as well as a substantial threat to mortality (Babin et al., 2008). These challenges have a notable impact on patient psychological wellbeing. Rates of emotional distress are high among HNC patients, with elevated depression and anxiety symptoms evident at all stages of the disease trajectory (Howren, et al., 2013).

In light of the difficulties that must be managed by this patient population, the importance of considering patient HRQL is increasingly recognised. Health-related quality of life reflects the degree to which an individual can function across a broad range of wellbeing domains, and the extent to which they can derive satisfaction from doing so; domains relate not only to physical functioning, but also social and psychological wellbeing (Morton & Izzard, 2003). By assessing HRQL it is possible to examine the impact of HNC and its treatment on all aspects of health, and better understand patient priorities for recovery. List and colleagues (2000) found that survival was not the top priority for a number of HNC patients, who instead reported that other factors (pain, energy, normal functioning, and appearance) were of greatest concern.

Identifying factors that contribute to patient HRQL may help to optimise outcomes following HNC treatment. For most patients, HRQL is lowest during treatment (Hammerlid et al., 2001), gradually returning to pre-treatment levels approximately 1 year after diagnosis (Abendstein et al., 2005). Therefore, time of assessment influences patient reports of HRQL, highlighting the utility of longitudinal research that allows for the identification of changes over time. Such research suggests that a subgroup of HNC patients experience enduring impairments in HRQL (e.g. Mehanna & Morton, 2006). While medical variables, such as treatment type, cancer stage, the presence of a feeding tube, and comorbidities have been related to patient HRQL (Bjordal et al., 2001; Terrell et al., 2004), they are not always associated with this outcome (Babin et al., 2008), particularly several years post-diagnosis (Hammerlid & Taft, 2001). Furthermore, psychological variables, such as depressive symptoms, have been found to explain variation in HNC patient HRQL independent of cancer characteristics (Howren et

al., 2013). Understanding factors that contribute to this variation is important, given well-documented associations between HRQL and clinical outcomes, including psychological distress (Kim et al., 2016), and disease-specific and overall survival (Abendstein et al., 2005).

In comparison to other cancers, limited attention has been paid to the factors that may explain variation in HNC patient HRQL and psychological wellbeing. However, there is some evidence to suggest that patients' perceptions of HNC play a role (Llewellyn et al., 2007a; Scharloo et al., 2010). The idea that people actively try to make sense of and manage health threats was proposed by Leventhal and colleagues (1980). According to the CSM, people form parallel cognitive and emotional representations of an illness based on their symptoms, past experiences, and environment. These representations (or beliefs) guide the adoption of coping behaviours intended to reduce health threats, and appraisal of progress feeds back into the model. Five key components of cognitive illness representations have been identified: illness identity (the illness the person is believed to have and its perceived symptoms), cause (what is believed to have caused the illness), timeline (how long the illness is expected to last), consequences (the perceived physical and social impact of the illness), and control (the extent to which the illness is believed to be curable or controllable) (Leventhal et al., 1984). Emotional representations include beliefs about the emotional impact of the illness. More recently, patients' overall coherence or understanding of their illness has been included in the assessment of illness perceptions (Moss-Morris et al., 2002).

Little research has investigated HNC patients' illness perceptions over time. Two cross-sectional studies have demonstrated relationships between illness perceptions and different aspects of HRQL, including physical, role, and emotional function (Llewellyn et al., 2007a; Scharloo et al., 2005). One longitudinal study showed that less belief in one's own behaviour causing HNC at diagnosis predicted better functioning and global health 2 years later (Scharloo et al., 2010). Perceiving a long timeline and many consequences of HNC also predicted worse HRQL at 2 year follow-up. A second longitudinal study found that although illness perceptions did not predict HRQL, long timeline beliefs prior to treatment were related to increased depression symptoms 6-8 months later (Llewellyn et al., 2007b). These findings reveal the importance of multiple assessments to identify the dynamic relationships between HNC patient illness perceptions and outcomes over time, and suggest that further longitudinal research is needed.

In other patient groups, attention has been paid to how the illness perceptions of informal caregivers may contribute to patient outcomes (e.g. Kaptein et al., 2007; Searle et al., 2007; Sterba et al., 2008). Informal caregivers may include spouses, family members, or close friends of a patient, who provide physical and emotional support at diagnosis and throughout treatment and recovery (Longacre et al., 2012). Limited research has been conducted in individuals caring for patients with HNC, despite evidence that these caregivers report high levels of strain and burden (Ross et al., 2010), as well as psychological distress (Hodges & Humphris, 2009). Even fewer studies have examined illness perceptions and coping behaviours in HNC caregivers, and whether these influence patient HRQL and psychological wellbeing. A cross-sectional study involving those caring for patients with oesophageal cancer found that caregiver perceptions of consequences and coherence contributed to patient anxiety and depression, respectively (Dempster et al., 2011a). Our own work has shown that interactions between patient and caregiver illness perceptions at diagnosis were cross-sectionally related to patient HRQL (Richardson et al., 2015a). However, the only studies investigating caregiver perceptions of HNC are cross-sectional, limiting conclusions about the predictive capacity of caregiver illness perceptions, and their importance to patient recovery over time (Sterba et al., 2016).

Research suggests that it is important to consider the degree of similarity between patient and caregiver illness perceptions, and how this affects patient outcomes. While this is yet to be explored in those managing HNC, longitudinal research has demonstrated that similar patient and caregiver illness perceptions are associated with positive patient outcomes in other illnesses. For example, Figueiras and Weinman (2003) found similar positive perceptions of myocardial infarction between patients and their spouses were associated with better patient physical, psychological, and sexual functioning; less patient disability; and greater dietary changes up to 1 year later. Similar positive perceptions between women with rheumatoid arthritis and their husbands have also predicted better psychological adjustment at 4 month follow-up (Sterba et al., 2008). In contrast, dissimilarities in illness perceptions between patients and their caregivers have been found to negatively impact patient (Heijmans et al., 1999) *and* caregiver psychological wellbeing (Richards et al., 2004; Twiddy et al., 2012) in studies involving individuals affected by AD, CFS, stroke, and psoriasis.

To date, changes in HNC patient and caregiver illness perceptions over time have not been examined. The importance of similarity or discrepancy between HNC patient and caregiver perceptions at diagnosis and future patient HRQL is also yet to be established. Therefore, the aims of this study were: 1) to examine changes in illness perceptions from diagnosis to 6 months in patients and

caregivers; 2) to assess changes in the degree of similarity between patients and caregivers over the same period; and 3) to investigate whether discrepancy between patient and caregiver illness perceptions at diagnosis was related to patient HRQL 6 months later. It was hypothesised that differences in illness perceptions between HNC patients and their caregivers at diagnosis would reduce over time as both parties learned more about the disease. Based on the results of other studies, we also hypothesised that discrepancy between patient and caregiver illness perceptions at diagnosis would predict lower subsequent patient HRQL.

Methods

Participants

A consecutive sample of patients and their caregivers attending the head and neck outpatient clinic at Auckland City Hospital, New Zealand, between February and October 2013, were invited to participate. Approximately 5-10 patients who met inclusion criteria were present at each clinic session (held once per week) and approximately 65% of patients also had a caregiver in attendance. To be included, patients were required to have received a diagnosis of primary epithelial head and neck cancer (i.e. carcinoma in the pharynx, larynx, oral cavity, sinonasal cavity), or a metastatic skin cancer in the head and neck region, within 3 weeks prior to their clinic attendance. In order to minimise loss to follow-up, patients were excluded if they were to be treated with palliative intent. Caregivers in attendance at the clinic were included; specifically, individuals identifying as a spouse, family member, close friend, or formal caregiver of the patient. Patients or caregivers were excluded if they had any condition that would interfere with their participation, including insufficient English language, cognitive impairment, physical disability, or severe mental illness.

Participant characteristics are presented in Table 7. Seventy-three patients and caregivers completed the questionnaires at the initial assessment. Sixty-two dyads completed every item on each illness perception questionnaire. The item most commonly missed was the timeline item. A total of 42 dyads returned the questionnaires again 6 months later. Reasons for not completing the follow-up questionnaires included: the patient having died or being too unwell ($n = 9$), either the patient or their caregiver reporting that it was too distressing ($n = 3$), being non-contactable ($n = 6$), only one member of the dyad completing the questionnaires ($n = 9$), and issues with the mailing system ($n = 3$). After accounting for those patients who died or were too unwell to complete the follow-up, the response rate was 66% (42/64).

Table 7. Demographic and medical characteristics of patients and caregivers at diagnosis

	Patients (n = 42)	Caregivers (n = 42)
Gender		
Male	29 (69%)	6 (14%)
Female	13 (31%)	36 (86%)
Ethnicity		
New Zealand European	33 (79%)	35 (84%)
Māori	7 (17%)	3 (7%)
Chinese	1 (2%)	1 (2%)
Other	1 (2%)	3 (7%)
Marital Status		
Single	4 (10%)	2 (5%)
Married	32 (76%)	36 (86%)
Divorced	1 (2%)	4 (9%)
Widowed	5 (12%)	
Smoking Status		
Yes	9 (21%)	3 (7%)
No	33 (79%)	39 (93%)
Cancer Type		
Oral Cavity, Pharynx, Larynx	35 (83%)	
Metastatic Skin Cancer	7 (17%)	
Cancer Stage		
I-II	16 (38%)	
III-IV	26 (62%)	
Treatment		
Surgery	13 (31%)	
Radiotherapy	29 (69%)	
Modality		
Single Modality Treatment	21 (50%)	
Combined Modality Treatment	21 (50%)	
Relationship to Patient		
Spouse/Partner		25 (60%)
Family Member		12 (29%)
Friend		4 (10%)
Formal Caregiver		1 (2%)

Power Analysis

In a sample of 42 patient-caregiver dyads, Twiddy et al. (2012) showed that discrepancy in perceptions of consequences of stroke predicted variation in patient distress scores ($\beta = 6.48$, $SE = 2.91$, $p = .03$), representative of a large effect. G-power software (Faul et al., 2007) indicated that 40 HNC patient-caregiver dyads would be needed in order to detect a large effect of discrepancy ($f^2 = .35$) using regression analyses, setting power at .80 and alpha at .05.

Procedure

Patients and their caregivers were approached after having seen the multidisciplinary HNC team. Written informed consent was obtained from those who were interested, following which

participants completed a questionnaire assessing perceptions of HNC. Patients also completed a HRQL measure. Six months later patients and their caregivers were contacted by phone and asked to complete the questionnaires for a second time. Questionnaires were posted to participants with a freepost return envelope.

Measures

Functional Assessment of Cancer Therapy – Head and Neck (FACT-H&N)

The FACT-H&N is a self-report instrument designed to assess quality of life. The questionnaire contains four subscales with 27 items that index physical, social, emotional, and functional wellbeing (Cella et al., 1993). Subscales are supplemented with a further 12 items that assess HNC-related symptoms. Higher scores on each subscale are indicative of better HRQL. The questionnaire produces a total score which is the sum of each subscale, including the HNC specific subscale. The total score was selected as the outcome of interest because it provides the most global indication of patient HRQL, indexing both physical and psychological function. The FACT-H&N is sensitive to clinical change in patients with HNC (Cella et al., 1993), and has been shown to be reliable and valid in a New Zealand context (Richardson et al., 2015a).

Brief Illness Perception Questionnaire (B-IPQ)

The Brief-IPQ consists of nine items, each assessing one dimension of illness perceptions (Broadbent et al., 2006). Five items index cognitive representations (consequences, timeline, personal control, treatment control, and identity), two items index emotional representations (concern and emotion), and one item indexes illness comprehensibility. Each item is rated on a 10-point Likert scale, with higher scores representing stronger perceptions. The questionnaire also contains one open-ended item that asks patients to list the three most important causes of their illness. The Brief-IPQ has demonstrated good test-retest reliability, and good convergent and predictive validity in a diverse range of patient groups, including New Zealand samples (Broadbent et al., 2015).

Caregiver Brief Illness Perception Questionnaire

A caregiver version of the Brief-IPQ was administered to caregivers, with items re-worded in order to investigate their perceptions of HNC. This is a method that has been used in previous studies

in New Zealand e.g. Broadbent et al. (2009a). For perceptions of consequences, timeline, personal control, treatment control, and illness identity, caregivers reported their perceptions of the patient's life. For example, 'How much do you think your family member's head and neck cancer affects *his/her* life?' For perceptions of concern, coherence, and emotional impact, caregivers reported on their perceptions of HNC in relation to their own life. For example, 'How much does your family member's head and neck cancer affect *you* emotionally?'

Analysis

Analyses were conducted using SPSS version 21. Descriptive statistics were used to summarise all variables. In order to examine whether patients and caregivers who returned the follow-up questionnaires differed from those who did not return them, chi square analyses were performed on categorical variables and independent t-tests on continuous variables.

The remainder of the analyses were performed on the 42 patients and caregivers who completed questionnaires at both time points. Independent sample t-tests were used to investigate whether there were any differences in illness perceptions based on patient cancer stage and treatment type. Paired sample t-tests were employed to investigate whether there were any significant differences between patients' and caregivers' illness perceptions, both at diagnosis and at 6 month follow-up. Paired sample t-tests were also used to investigate whether there were any significant changes in perceptions and HRQL over time within groups. Correlation analyses were conducted to examine the relationship between patient and caregiver illness perceptions at each assessment point.

The APIM (Cook & Kenny, 2005) was used as a method for determining the impact of both patient and caregiver perceptions at diagnosis, and the discrepancy between these perceptions, on patient HRQL 6 months later. The *actor* effect presented in the analyses represents the impact of the patient's own illness perception on their subsequent HRQL. In contrast, the *partner* effect represents the impact of the caregiver's illness perception on patient HRQL. The degree of discrepancy between patient and caregiver illness perceptions was established by calculating the absolute difference between each dyad's score for each illness perception dimension, a method that has been used in recent studies adopting the APIM (e.g. Twiddy et al., 2012). Specifically, each caregiver score was subtracted from the score of the associated patient, ignoring any differences in direction. Linear mixed models were used to analyse the dyadic data. Due to the small sample size, individual models were

created to investigate the effects of each illness perception dimension. The effects of the variables under investigation were estimated in stages. In the first step, patient HRQL at baseline was placed into the model to account for its influence on follow-up HRQL prior to the inclusion of illness perceptions. In the second step, illness perception scores for each member of the dyad as well as dyad discrepancy scores were entered to estimate the influence of actor and partner effects and the impact of discrepancy on patient HRQL.

Results

There were no significant differences between patients and caregivers who completed the questionnaires only at diagnosis ($n = 73$) and those who also completed questionnaires 6 months later ($n = 42$) with respect to medical and demographic characteristics, illness perceptions, and HRQL.

Relationships between Illness Perceptions, Cancer Stage, and Treatment

No relationship was found between patient cancer stage and illness perceptions at diagnosis with respect to consequences, personal control, treatment control, illness identity, concern, and coherence. However, patients with an advanced cancer stage (III-IV) ($M = 4.89$, $SD = 2.98$) were more likely to perceive a longer timeline than those with an earlier stage cancer (I-II) ($M = 4.89$, $SD = 2.98$), $t(66) = -2.04$, $p = .045$, and patient and caregiver perceptions were more likely to be discrepant among patients with an early stage cancer ($M = 3.90$, $SD = 2.55$) compared to a later stage ($M = 2.26$, $SD = 2.33$), $t(61) = 2.53$, $p = .014$. While patient perceptions of emotional impact did not significantly differ based on cancer stage, caregiver perceptions did. Those caring for a patient with an advanced cancer ($M = 7.21$, $SD = 2.28$) reported a greater emotional impact than those caring for a patient with an earlier cancer stage ($M = 5.84$, $SD = 2.51$), $t(71) = -2.35$, $p = .021$.

With respect to treatment, patients who received radiotherapy ($M = 4.89$, $SD = 2.84$) were more likely to perceive a longer timeline than those who did not ($M = 3.19$, $SD = 3.50$), $t(66) = -2.12$, $p = .037$. The discrepancy between patient and caregiver timeline perceptions was greater among patients who received surgery ($M = 4.25$, $SD = 2.47$) compared to patients who received radiotherapy ($M = 2.09$, $SD = 2.23$), $t(61) = 3.45$, $p = .001$. Patients who received surgery ($M = 9.10$, $SD = 1.45$) perceived greater treatment control than patients who had radiotherapy ($M = 8.14$, $SD = 2.32$), $t(68) = 2.08$, $p = .042$, and perceived fewer symptoms ($M = 2.96$, $SD = 3.28$) compared to radiotherapy patients ($M = 4.58$, $SD = 2.87$), $t(71) = -2.10$, $p = .039$.

Differences in Illness Perceptions between HNC Patients and Caregivers

Table 8 presents descriptive statistics summarising patient and caregiver illness perceptions. Caregivers had more negative perceptions of HNC than patients at both time points. Specifically, caregivers perceived more consequences of the disease, believed it would last for a longer time, and had higher levels of concern than patients at baseline and again 6 months later. Caregivers also perceived lower perceptions of treatment control than patients at baseline and reported greater emotional impact, although these differences were no longer significant at the 6 month follow-up. At 6 months, caregivers perceived significantly more symptoms of HNC than patients.

Table 8. Differences between patient and caregiver illness perceptions at diagnosis and 6 months

	Diagnosis								6 Month Follow-Up							
	Patient		Caregiver		t	r	Discrepancy		Patient		Caregiver		t	r	Discrepancy	
	M	SD	M	SD			M	SD	M	SD	M	SD			M	SD
Illness Perceptions																
Consequences	4.00	3.29	6.14	2.70	-3.47**	.12	3.67	2.63	4.50	3.31	6.62	2.88	-3.78**	.32*	3.31	2.57
Timeline	3.94	3.16	5.86	2.91	-3.42*	.39*	2.81	2.64	3.69	3.32	4.92	3.59	-2.21*	.54**	2.61	2.35
Personal Control	3.48	3.09	3.68	3.00	-0.40	.47*	2.35	2.05	4.46	3.73	3.79	3.50	0.88	.13	3.54	3.20
Treatment Control	8.61	2.11	7.73	1.98	2.05*	.09	2.24	1.79	8.70	2.08	8.63	2.00	0.29	.68**	0.93	1.33
Illness Identity	4.14	3.12	4.05	2.65	0.23	.57**	2.10	1.71	3.85	2.93	5.25	3.06	-2.54*	.32*	2.85	2.41
Concern	7.33	2.89	8.45	1.98	-2.23*	.15	2.26	2.57	4.32	3.58	6.10	2.96	-3.08*	.37*	3.34	2.35
Coherence	5.79	2.94	6.79	2.76	-1.74	.15	2.95	2.45	7.43	2.98	8.62	1.25	-2.17*	-.29	2.52	2.74
Emotional Impact	4.74	3.17	6.40	2.32	-2.84*	.06	3.43	2.31	3.55	3.25	4.71	3.01	-1.92	.21	2.98	2.80

Note. * = $p < .05$, ** = $p < .001$. M = mean, SD = standard deviation. r = correlation between patient and caregiver perceptions. Discrepancy = absolute difference score calculated by subtracting each patient perception score from each caregiver perception score.

Patient and caregiver illness perceptions were significantly positively intercorrelated for several dimensions. Timeline and illness identity perceptions were significantly correlated at both diagnosis and follow-up. Personal control perceptions were correlated at diagnosis only, while consequences, treatment control, and concern were significantly correlated at 6 months.

Changes in Illness Perceptions and Patient HRQL

Both patients and caregivers experienced a significant reduction in illness concern over time ($t(41) = 5.24, p < .001$ and $t(41) = 5.35, p < .001$, respectively). Perceptions of emotional impact also reduced significantly over time in both patients ($t(41) = 2.40, p = .021$) and caregivers ($t(41) = 3.83, p < .001$). Caregivers' perceptions of treatment control ($t(40) = -2.77, p = .009$) and symptoms (identity) ($t(40) = -2.59, p = .013$) increased from diagnosis to 6 months, although patients' perceptions on these dimensions did not. No significant difference in discrepancy scores between diagnosis and 6 month follow-up was found for perceptions of consequences, timeline, coherence, or emotional impact. However, a difference was found regarding discrepancy in perceptions of personal control ($t(40) = -2.18, p = .036$), illness identity ($t(40) = -1.99, p = .054$), and concern ($t(41) = -1.84, p = .073$), with these perceptions more discrepant at 6 months compared to diagnosis. In contrast, perceptions of treatment control became less discrepant over time ($t(40) = 3.83, p < .001$). These results suggest that patients and caregivers became less similar with respect to perceptions of personal control, illness identity, and concern, and more similar regarding perceptions of treatment control. No change in patient HRQL was noted from diagnosis ($M = 118.57, SD = 20.63$) to 6 months ($M = 118.00, SD = 20.02$), $t(41) = .28, p = .785$.

Baseline Predictors of Patient HRQL

The APIM regression models displayed in Table 9 show baseline predictors of patient HRQL. Patient HRQL at baseline was a significant predictor of follow-up HRQL in all models. In model 1, greater discrepancy between patient and caregiver timeline perceptions at diagnosis was a significant predictor of lower subsequent patient HRQL. In model 2, patient perceptions of personal control were a significant predictor of HRQL at follow-up. Furthermore, the discrepancy between patient and caregiver perceptions of personal control contributed additional variance in HRQL, with greater discrepancy predicting lower patient HRQL scores. In model 3, greater discrepancy in symptom perception scores significantly contributed to lower patient HRQL. In model 4, both patient and caregiver perceptions of

illness coherence made a significant contribution to patient HRQL, but not the discrepancy score. High patient coherence at diagnosis was associated with better future HRQL and, conversely, high caregiver coherence was related to lower patient HRQL. No other relationships were found between patient and caregiver illness perceptions, their discrepancy, and patient HRQL over this time.

Table 9. Summary of APIM regression models: baseline predictors of patient HRQL at 6 months

	B	SE	β	<i>p</i>	CI	
Step 1						
Baseline patient HRQL (actor effect)	0.74	0.09	.78	.000	0.55	0.93
Step 2						
<i>Model 1</i>						
Patient timeline perception (actor effect)	-0.84	0.73	-.13	.254	-2.32	0.64
Caregiver timeline perception (partner effect)	-1.33	0.85	-.19	.126	-3.06	0.40
Discrepancy in timeline perceptions	-1.93	0.92	-.24	.044	-3.80	-0.06
<i>Model 2</i>						
Patient personal control perception (actor effect)	1.86	0.66	.28	.008	.52	3.21
Caregiver personal control perception (partner effect)	0.89	0.60	.14	.148	-.33	2.11
Discrepancy in personal control perceptions	-1.83	0.76	-.21	.021	-3.37	-0.30
<i>Model 3</i>						
Patient illness identity perception (actor effect)	-0.84	0.87	-.13	.337	-2.59	0.91
Caregiver illness identity perception (partner effect)	0.33	0.77	.05	.674	-1.23	1.89
Discrepancy in illness identity perceptions	-2.35	0.95	-.24	.018	-4.27	-0.42
<i>Model 4</i>						
Patient coherence perception (actor effect)	1.88	0.66	.27	.007	.54	3.22
Caregiver coherence perception (partner effect)	-1.82	0.69	-.24	.012	-3.21	-0.43
Discrepancy in coherence perceptions	0.77	0.83	.09	.357	-.90	2.45

Note. $n = 42$ dyads. Actor effect = intra-individual effects. Partner effect = effect of caregiver illness perceptions on patient HRQL. Step 1 = modelling baseline HRQL only. Step 2 = multivariate model with patient and caregiver illness perceptions and discrepancy scores, controlling for actor and partner effects.

Cross-sectional Predictors of Patient HRQL

Table 10 includes APIM regression models showing the contributions of illness perceptions at 6 months to patient HRQL at this time point (after controlling for HRQL at baseline). In model 1, caregiver perceptions of many consequences of the disease were associated with lower patient HRQL. In model 2, both patient coherence perceptions and the discrepancy score made significant contributions to patient HRQL. Interestingly, greater discrepancy in coherence perceptions was associated with better HRQL. In model 3, patient perceptions of a strong emotional impact were associated with lower HRQL. No other patient and caregiver illness perceptions made a significant contribution.

Table 10. Summary of APIM regression models: cross-sectional predictors of patient HRQL at 6 months

	B	SE	β	p	CI	
Step 1						
Baseline patient HRQL (actor effect)	0.74	0.09	.78	.000	0.55	0.93
Step 2						
<i>Model 1</i>						
Patient consequences perception (actor effect)	-1.26	0.68	-.21	.073	-2.64	0.12
Caregiver consequences perception (partner effect)	-1.37	0.65	-.20	.043	-2.69	-0.05
Discrepancy in consequences perceptions	0.35	0.77	.05	.647	-1.20	1.91
<i>Model 2</i>						
Patient coherence perception (actor effect)	2.73	1.36	.42	.052	-0.02	5.48
Caregiver coherence perception (partner effect)	-2.49	1.45	-.17	.095	-5.43	0.45
Discrepancy in coherence perceptions	3.24	1.52	.44	.039	0.17	6.30
<i>Model 3</i>						
Patient emotion perception (actor effect)	-1.91	0.63	-.32	.004	-3.18	-0.64
Caregiver emotion perception (partner effect)	0.04	0.64	.01	.947	-1.25	1.34
Discrepancy in emotion perceptions	1.07	0.70	.15	.136	-0.35	2.48

Note. $n = 42$ dyads. Actor effect = intra-individual effects. Partner effect = effect of caregiver illness perceptions on patient HRQL. Step 1 = modelling baseline HRQL only. Step 2 = multivariate model with patient and caregiver illness perceptions and discrepancy scores, controlling for actor and partner effects.

The above results were performed with and without the inclusion of the dyad that comprised a patient and formal caregiver. This did not make a significant difference to any findings. Furthermore, no differences were found when including cancer stage as a covariate in each APIM model.

Discussion

This is the first longitudinal study to report changes in illness perceptions over time in both patients with HNC and their caregivers, and to show that discrepancy in these perceptions at diagnosis is related to patient HRQL 6 months later.

Previous cross-sectional results for this sample documented that caregivers had more negative perceptions about the consequences, timeline, treatment, concern, and emotional impact of HNC at diagnosis (Richardson et al., 2015a). These follow-up results show that caregivers continued to be more negative than patients about the consequences, timeline, and concern associated with HNC. Interestingly, caregivers also perceived more patient symptoms at 6 months than patients themselves. Greater negativity in caregiver perceptions has been documented across a wide range of illness groups (Kaptein et al., 2007; Karademas et al., 2010; Twiddy et al., 2012). A possible explanation for this is that caregivers are more realistic than patients, who may hold self-protective beliefs about their

illness (Jemmott et al., 1986). Those caring for patients with HNC have been found to report higher levels of anxiety than patients (Longacre et al., 2012), as well as difficulties coping (Nightingale et al., 2016b), which could also contribute to more negative perceptions.

Both patients and caregivers had a decrease in perceptions of concern and emotional impact from diagnosis to 6 months. Other studies have found that the emotional impact of HNC lessens over time (Haisfield-Wolfe et al., 2009), although it is important to note that significant distress can be detected as many as 7-11 years post-treatment (Bjordal & Kaasa, 1995). In the present study, patient perceptions of emotional impact at 6 months were significantly associated with concurrent HRQL scores. This suggests that the emotional and functional impacts of the illness are strongly linked.

Moderate to strong positive intercorrelations were found between patient and caregiver illness perceptions at both time points, in keeping with research in other patient groups, such as stroke (Twiddy et al., 2012) and heart disease (Benyamini, Medalion, & Garfinkel, 2007). However, discrepancies in these illness perceptions were noted at both time points, perhaps reflecting the greater negativity of caregiver perceptions. Furthermore, a number of patient and caregiver illness perceptions became more discrepant (less similar) from diagnosis to 6 months, including perceptions of personal control, illness identity, and concern. The different roles of patients and their caregivers may result in different experiences and contribute to unique perspectives of the same disease. For example, caregivers may consider it their role to keep close note of patients' symptoms and to maintain concern for patient wellbeing (Ross et al., 2010), while patients focus on recovery and moving on as quickly as possible. Increases in discrepancy may also be attributable to caregivers receiving less information about HNC than patients over time (Humphris & Hodges, 2009). Patient and caregiver perceptions of treatment control became more similar across the study period. It is likely that as time passes, both patients and caregivers develop more accurate perceptions about the impact and effectiveness of treatment, increasing the alignment of these perceptions as a result.

The longitudinal design enabled us to determine that the degree of discrepancy between patient and caregiver illness perceptions at diagnosis predicted future patient HRQL. Greater discrepancy was consistently related to lower HRQL scores. Discrepancy in perceptions of timeline, personal control, and illness identity each made a significant contribution in the first APIM, even after controlling for the influence of patients' and caregivers' own perceptions, as well as patient HRQL at baseline. This suggests that it is particularly challenging for patients when their caregivers differ in their

beliefs regarding how long HNC will last, the patient's capacity to manage the disease, and the degree to which they are experiencing symptoms. Patients may have a sense of disconnect with their caregiver when discrepancy is high. This could lead to conflict, or alternatively, diminished feelings of closeness and mutual understanding.

The findings highlight the importance of investigating illness perceptions in patient-caregiver dyads over time in order to capture their effects on patient outcomes. Unfortunately, the number of longitudinal studies investigating dyads is low in cancer patients generally, and particularly so in patients with HNC (Sterba et al., 2016). This is despite the fact that a cancer diagnosis and treatment invariably occur in a context, whereby patient recovery can be influenced by close others and their accompanying beliefs and behaviours (Berg & Upchurch, 2007). Other studies have demonstrated an impact of discrepancy between patient and caregiver illness perceptions on patient wellbeing (e.g. Figueiras & Weinman, 2003), although most findings have been cross-sectional. Twiddy and colleagues (2012) investigated patient and caregiver perceptions of stroke at two time points. Discrepancy in illness perceptions at Time 1 did not predict patient or caregiver distress at Time 2. However, discrepancy in perceptions of consequences and coherence at Time 2 was associated with greater patient distress at this time point. Similarly, we found that discrepancy in coherence perceptions at 6 month follow-up was directly related to patient HRQL.

Individual patient and caregiver illness perceptions at diagnosis were also predictive of HRQL. Patients who perceived high personal control at diagnosis reported better HRQL at 6 month follow-up, even when accounting for initial HRQL status. Research in other patient groups has found that greater perceived control is linked to higher HRQL (Hernandez-Tejada, Lynch, Strom, & Egede, 2012), while low control perceptions are associated with psychological distress (Paschalides et al., 2004). However, factors that mediate the relationship between perceived control and health outcomes are poorly understood (Gerstorff, Rocke, & Lachman, 2011). Patient and caregiver coherence at diagnosis also made a significant contribution to future patient HRQL. Interestingly, while high patient coherence was related to better HRQL, high caregiver coherence was associated with worse HRQL. This is consistent with the results of Dempster and colleagues (2011a), where oesophageal cancer patient depression was highest when patients had low illness coherence but their caregivers had high coherence.

This study has several strengths, including a longitudinal design, investigation of an understudied patient population, and use of the APIM. The longitudinal design made it possible to

examine the predictive power of patient and caregiver illness perceptions, as well as the way in which these perceptions changed over time as individuals developed a more nuanced understanding of HNC. The APIM analyses allowed for an examination of discrepancy in illness perceptions after first controlling for patient and caregiver scores in the models, reducing multicollinearity. However, there are a number of limitations to consider. First, the small sample size investigated made it necessary to investigate an individual regression model for each illness perception dimension. Therefore, the results presented in these models should be considered exploratory. Second, caregivers were a heterogeneous group. Although this may increase the generalisability of our findings, it may be that the results are stronger for subsets of the caregivers examined (e.g. spouses). Similarly, it was not a requirement for caregivers to be living with the patient. Third, there are recognised limitations of using single item measures, such as the Brief-IPQ. While this is a widely used instrument with sound psychometric properties (Broadbent et al., 2015), it is not possible to calculate internal consistency coefficients as an index of reliability. Finally, we did not investigate whether discrepancy in illness perceptions was related to caregiver quality of life. The psychological adjustment of HNC caregivers is an understudied phenomenon (Ross et al., 2010), and research in other patient groups suggests that discrepancies in patient and caregiver illness perceptions are related to caregiver wellbeing (Richards et al., 2004).

The study has implications for the design of psychological interventions for patients with HNC. Psychological interventions could be developed with an aim to align patient and caregiver perceptions, and encourage accurate yet optimistic beliefs. This may be challenging when patients are facing such a serious disease, yet might be achieved using psychoeducation strategies, such as providing patients and caregivers with information and adaptive coping skills (Golant, Altman, & Martin, 2003). The impact of HNC and its treatment on HRQL are considerable and can exceed the impact of other chronic illnesses (Howren et al., 2013). Therefore, strategies to improve HRQL in this patient group are of great importance.

In conclusion, this study has shown that both patient and caregiver perceptions of concern and emotional impact decreased from HNC diagnosis to 6 months later, while caregiver perceptions of treatment control and identity increased. Patients and caregivers became more similar over time with respect to perceptions of treatment control and less similar regarding personal control, illness identity, and concern perceptions. Finally, greater discrepancy between patient and caregiver perceptions of timeline, personal control, and illness identity at diagnosis predicted worse patient HRQL at 6 month

follow-up. Therefore, it is recommended that caregivers are involved in discussions between patients and health care professionals, and incorporated into psychological interventions that aim to improve HRQL in patients with HNC.

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Chapter 5. Patient Coping Strategies at Diagnosis and Subsequent Psychological Adjustment

Preface

In this chapter, the focus shifts from illness perceptions to consider the coping aspect of the self-regulatory process and how this may be related to psychological outcomes among patients with HNC. According to the CSM, an individual's representation of their illness will guide the adoption of coping behaviours designed to manage the illness and facilitate a return to good health (Diefenbach & Leventhal, 1996). Illness perceptions and coping strategies may be modified following the appraisal of the success or failure of coping at achieving desired health outcomes (Leventhal et al., 1980). While the CSM initially conceptualised coping strategies as the behavioural outcomes of individual illness perceptions (such as medication adherence and self-care), there has since been a shift to view coping as a broader concept that includes both cognitive and emotional strategies designed to deal with threats to physical health (Dempster et al., 2015). These strategies can include engagement and disengagement approaches, as well as emotion-focused and problem-focused techniques (see Chapter 2).

The application of the CSM to the investigation of psychological outcomes in individuals with chronic health conditions has been variable with respect to coping. Although most investigations hypothesise that both illness perceptions and coping strategies will contribute to patient psychological wellbeing, some studies propose that relationships between illness perceptions and wellbeing will be mediated by coping (Evans & Norman, 2012; Knibb & Horton, 2008; Rutter & Rutter, 2002), whereas others make no assumptions about mediation (Benyamini, Goner-Shilo, & Lazarov, 2012; Price et al., 2012). However, concerns regarding the investigation of mediation have been raised with respect to the CSM. This is because the model maintains that a person's cognitions will influence behaviour at one point in time. Given that cognitions and associated coping behaviours are dynamic, relationships between these variables may not necessarily extend to influence future outcomes (Llewellyn et al., 2007b). Furthermore, the impact that illness perceptions have on coping may occur across a period too brief to capture using traditional research methods (Dempster et al., 2015), and there is evidence that responses on measures of illness perceptions may be confounded by appraisals of available coping resources (McCorry, Scullion, McMurray, Houghton, & Dempster, 2013).

Difficulties associated with the investigation of coping as a mediator are evident in the results of studies that have endeavoured to capture this process. A recent review of 31 studies using the CSM as a theoretical basis found that evidence for a mediating effect of coping on the relationship between illness perceptions and psychological outcomes (depression, anxiety, and quality of life) was inconsistent across different physical health conditions (Dempster et al., 2015). Coping variables were found to be a stronger predictor of outcomes than illness perceptions. When considering patients with HNC, only two studies have examined coping as a mediator of the relationship between illness perceptions and psychological wellbeing (Dempster et al., 2011a; Llewellyn et al., 2007b). No evidence for mediation was found in either of these investigations, although both illness perceptions and coping were unique predictors of HNC patient distress.

The limited evidence for coping mediating associations between illness perceptions and psychological outcomes, as well as problems associated with the simultaneous measurement of these constructs, suggest that it may be more appropriate to evaluate their effects separately. Indeed, a common problem with studies investigating both illness perceptions and coping is that the effects of illness perceptions on outcomes are considered first (primarily using regression analyses). This can result in little added variance from coping and lead to underestimations of the contribution that coping makes to psychological wellbeing (Dempster et al., 2015). Additionally, the CSM proposes that coping will have direct associations with health (in contrast to illness perceptions which are proposed to have indirect relationships), an idea that is communicated in other well-validated theoretical models. For example, the Transactional Model of Stress and Coping (Lazarus, 1966; Lazarus & Folkman, 1984) maintains that coping efforts employed to manage stressful events will be directly related to outcomes, including health behaviours, emotional wellbeing, and functional status.

Studies involving both healthy and patient populations (Moskowitz, Hult, Bussolari, & Acree, 2009; Penley, Tomaka, & Wiebe, 2002; Taylor & Stanton, 2007), including patients with cancer (Hoyt, Thomas, Epstein, & Dirksen, 2009; Stanton, Danoff-burg, & Huggins, 2002), have provided strong evidence for a relationship between coping and physical and psychological health outcomes. Numerous studies have also identified that ways of coping are associated with psychological outcomes in patients with HNC, with the largest evidence base demonstrating a link between the use of disengagement coping strategies and higher levels of distress and lower HRQL in the post-treatment phase (Aarstad et al., 2011a; Elani & Allison, 2008; Johansson et al., 2011; List et al., 2002).

One of the aims of this thesis includes identification of whether coping behaviours at *diagnosis* can predict variation in psychological outcomes. To date, studies that have investigated HNC patient coping at this time point have been cross-sectional, with the exception of two longitudinal investigations. Derks and colleagues (2005) documented associations between avoidant coping and higher levels of depression and low HRQL over time, although did not examine coping as a unique predictor of future outcomes. Llewellyn et al. (2007b) found that self-blame prior to treatment predicted greater depression, and that acceptance coping predicted lower HRQL and greater depression 6-8 months post-treatment. Therefore, available results regarding the longitudinal relationship between coping at HNC diagnosis and future outcomes are inconsistent.

The dearth of studies examining whether coping strategies at time of diagnosis can predict future psychological wellbeing among patients with HNC suggests that more research is needed. When utilising cross-sectional research designs it is impossible to determine whether coping is influencing the development of psychological difficulties, or these difficulties are interfering with an individual's capacity to cope. However, the majority of studies examining coping in patients with HNC have employed cross-sectional analyses, particularly those investigating links between coping and patient HRQL (e.g. Chaturvedi et al., 1996). A recent review concluded that it would be useful to establish how coping strategies interact with HRQL across the disease trajectory in order to ascertain when interventions designed to improve coping would be most appropriate (Dunne et al., 2016).

Another outcome which may have an important relationship with coping in patients with HNC is PTSD. Symptoms of post-traumatic stress are understudied in this patient group, despite the aggressive nature of treatment and the inherent threat of distressing long-term side effects, including visible disfigurement and functional difficulties relating to eating, breathing, and speech (van der Molen, van Rossum, Burkhead, Smeele, & Hilgers, 2009). Preliminary studies have shown that PTSD symptoms are prevalent approximately 4 weeks after HNC diagnosis (Posluszny et al., 2015), and even more prevalent 6 and 12 months later, affecting 20% of patients (Kangas et al., 2005a; Kangas et al., 2005b). There has been limited investigation of the factors that may contribute to PTSD in patients with HNC (as well as patients with other types of cancer). However, research in other individuals affected by PTSD has shown that coping strategies, particularly those characterised by disengagement and avoidance, are associated with PTSD symptom severity (Bryant & Harvey, 1995; Street, Gibson, & Holohan, 2005). Nevertheless, few studies have examined these relationships over time (Krause, Kaltman, Goodman, & Dutton, 2008).

The paper presented in this chapter describes an investigation of whether coping strategies at diagnosis are a unique predictor of variation in PTSD symptoms and HRQL 6 months later in patients with HNC. Elucidating relationships between coping and psychological outcomes over this period could help to determine whether it would be beneficial for psychological interventions to not only address illness perceptions, but also the way in which HNC patients cope with their diagnosis and treatment.

Citation

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Abstract

Background: Evidence suggests that patients with HNC are susceptible to PTSD. However, research is yet to examine predictors of PTSD symptoms in this patient group. The objective of this study was to investigate whether coping strategies at HNC diagnosis were related to outcomes of post-traumatic stress and HRQL 6 months later.

Methods: Sixty-five patients with HNC completed an assessment of coping, distress, and HRQL at diagnosis and again 6 months later, and an assessment of post-traumatic stress at 6 months. Correlations and regression analyses were performed to examine relationships between coping and outcomes over time.

Results: Regression analyses showed that denial, behavioural disengagement, and self-blame at diagnosis predicted post-traumatic stress symptoms. Self-blame at diagnosis also predicted poor HRQL.

Conclusions: Results have implications for the development of psychological interventions that provide alternative coping strategies to potentially reduce PTSD symptoms and improve HRQL.

Background

Head and neck cancer and its treatment are associated with disruption to patient HRQL, often resulting in problems with speech, swallowing, eating and breathing, and disfigurement (List & Bilir, 2004). These factors have implications for patient psychological wellbeing (Haisfield-Wolfe et al., 2009). Rates of depression and anxiety are higher in patients with HNC than any other cancer patient population (Singer et al., 2012), and preliminary evidence suggests that patients are susceptible to symptoms of PTSD (Kangas, Milross, Taylor, & Bryant, 2013).

Post-traumatic stress disorder is a psychiatric disorder that can develop after experiencing a traumatic event, involving physical harm or the threat of physical harm. Symptoms of PTSD are grouped into four broad categories, including heightened arousal, intrusive thoughts (re-experiencing the traumatic event), avoidance, and negative changes in cognitions and mood (APA, 2000). These symptoms cause clinically significant distress and impairment in important domains of function. A diagnosis of cancer is recognised as an event capable of eliciting PTSD by the American Psychiatric Association (APA, 1994). However, HNC may have greater potential to produce PTSD compared to other cancers given that the disease is not only life-threatening but also associated with highly aversive treatments applied to the head and neck region, which can have an enduring impact on basic functions and appearance (Posluszny et al., 2015).

To date, only two studies have investigated HNC-related PTSD. The first included both HNC and lung cancer patients and found that 22% met criteria for PTSD 6 months post-diagnosis (Kangas et al., 2005a). The most recent study found that 12% of patients with HNC met the criteria for PTSD between 4 and 16 weeks post-diagnosis (Posluszny et al., 2015). The lower rate of PTSD in this study may be attributable to the shorter time frame investigated. These findings suggest that more studies are needed to determine the prevalence of PTSD in patients with HNC and the factors that may contribute to its development. A recent meta-analysis that investigated the prevalence of cancer-related PTSD also concluded that more research to identify factors contributing to PTSD vulnerability is necessary (Abbey, Thompson, Hickish, & Heathcote, 2015).

One factor that has been associated with a range of psychological outcomes in patients with HNC is coping (Howren et al., 2013). Coping has been defined as “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p. 141). An important distinction in

coping is between behaviours characterised by engagement and those characterised by disengagement (Carver & Connor-Smith, 2010). Engagement-focused coping strategies include those aimed at actively dealing with a stressor (e.g. problem-focused coping, support seeking, and emotion regulation), while disengagement-focused strategies are characterised by avoidance or escape from the stressor and/or its associated distressing emotions (Skinner et al., 2003). Examples of disengagement/avoidant coping strategies include denial, self-distraction, and alcohol and drug use.

Available research suggests that when coping with an HNC diagnosis, engagement-focused coping strategies are related to positive outcomes, including benefit finding (Llewellyn et al., 2013; Cavell et al., 2016) and reduced distress (Karnell et al., 2007). Conversely, the use of disengagement/avoidant coping strategies has been related to low HRQL, anxiety, and depression. There is more evidence to support the adverse impact of disengagement coping than there is to support the beneficial effects of engagement coping in patients with HNC (Llewellyn et al., 2007b), as has been found in other cancer groups (Yang, Brothers, & Andersen, 2008).

Another coping strategy that has been related to poor psychological adjustment is self-blame. Behavioural self-blame can occur when individuals perceive that they could have done something differently to prevent or change their situation. This strategy may be particularly relevant to HNC patients, for whom cigarette smoking and alcohol use are established risk factors (Hashibe et al., 2007). Indeed, self-blame has been correlated with lower HRQL (Scharloo et al., 2005) and continued smoking in this patient group (Christensen et al., 1999). Self-blame has also been found to predict depression 6-8 months post-treatment for HNC (Llewellyn et al., 2007b). However, no prospective study has ascertained whether self-blame is associated with HNC patient HRQL or PTSD.

The objective of the present study was to investigate the influence of coping strategies at HNC diagnosis on PTSD symptoms and HRQL 6 months post-diagnosis. The focus was on coping with *diagnosis* in particular, given that this is a time of high distress (Neilson et al., 2013), and few longitudinal studies have examined whether coping at this time point is related to future psychological outcomes.

Methods

Participants

Participants were a consecutive sample of patients with HNC recruited from a head and neck outpatient clinic at a hospital in New Zealand, between February and October 2013. Patients were invited to take part in the study if they had a diagnosis of primary epithelial head and neck cancer (carcinoma in the pharynx, larynx, oral cavity, sinonasal cavity), or an advanced (metastatic) skin cancer in the head and neck region, within 3 weeks prior to attendance. Patients were excluded if they were unable to speak or read English, if they were to be treated with palliative intent, or if they had conditions that would interfere with participation (including cognitive impairment, physical disability, or psychiatric conditions). Participant characteristics are presented in Table 11.

Table 11. Demographic and medical characteristics of participants at diagnosis and 6 months

	Diagnosis (<i>n</i> = 91)	Follow-Up (<i>n</i> = 65)
Gender		
Male	70 (77%)	47 (72%)
Ethnicity		
New Zealand European	64 (70%)	49 (75%)
Māori	12 (13%)	8 (12%)
Other	15 (17%)	8 (13%)
Marital Status		
Single	11 (12%)	9 (14%)
Married	64 (70%)	44 (68%)
Divorced	8 (9%)	5 (7%)
Widowed	7 (8%)	7 (11%)
Smoking Status		
Yes	18 (20%)	15 (23%)
Type of Cancer		
HNC	79 (87%)	55 (85%)
Skin	12 (13%)	10 (15%)
HNC Site		
Oropharynx	14 (15%)	11 (17%)
Larynx	20 (22%)	13 (20%)
Oral Cavity	36 (40%)	26 (40%)
Hypopharynx	3 (3%)	1 (2%)
Nasopharynx	4 (5%)	1 (1%)
Other	14 (15%)	13 (20%)
Stage of Cancer		
I-II	33 (36%)	25 (38%)
III-IV	58 (64%)	40 (62%)

Ninety-one patients completed the questionnaires at diagnosis. Between diagnosis and 6 month follow-up, 15 patients died. Sixty-five of the 76 remaining participants returned follow-up questionnaires (response rate = 88%). No systematic differences were observed between those who returned the questionnaires and those who did not with respect to gender, ethnicity, marital status,

cancer site, cancer stage, or treatment modality. Reasons for failure to return the follow-up questionnaires included: feeling distressed ($n = 3$), being non-contactable ($n = 5$), and issues with the mailing system ($n = 3$).

Power Analysis

In previous research, avoidance coping at diagnosis predicted HNC patient depressive symptoms, representative of a medium effect size ($r = 0.34$) (de Leeuw et al., 2001). G-power (Faul et al., 2007) indicated that 49 patients would be needed to detect a similar effect (setting power at .80 and alpha at .05).

Procedure

Informed consent was obtained from all individual participants included in the study. Participants were asked to complete a booklet of questionnaires (assessing demographics, coping, HRQL, and distress) after diagnosis at their multidisciplinary clinic visit. They were mailed another questionnaire booklet 6 months later which contained the same measures, as well as an assessment of PTSD symptoms. Information on medical and treatment characteristics was collected from patient medical records. Approval was obtained from the University Human Participants Ethics Committee and the relevant District Health Board Research Review Committee.

Measures

Functional Assessment of Cancer Therapy – Head and Neck (FACT-H&N)

The FACT-H&N is a validated self-report instrument that assesses HRQL in patients with HNC, including physical, social, emotional, and functional wellbeing, as well as head and neck related symptoms (Cella et al., 1993). Each item is rated on a 0 to 4 scale. Scores on each subscale are summed to create a total HRQL score, with higher scores indicative of better quality of life. Reliability was satisfactory in this study ($\alpha = .78$).

General Health Questionnaire (GHQ-12)

The GHQ-12 is a 12-item questionnaire to identify distress in both general and clinical populations (Goldberg, 1992). Higher scores indicate higher distress, with scores greater than 15

indicating clinically significant distress symptoms. The GHQ-12 is a valid measure for detecting depressive symptoms in patients with cancer (Reuter & Harter, 2001), and has good internal consistency and test-retest reliability (Goldberg, 1992). Cronbach's alpha of the scale in this study was .91. Distress was assessed in order to control for scores at diagnosis when investigating the relationship between coping and subsequent PTSD.

Brief COPE

The Brief COPE is a valid and reliable self-report scale to assess different ways of coping (Carver, 1997). Subscales include self-distraction (in this study, $\alpha = .50$), active coping ($\alpha = .78$), denial ($\alpha = .80$), substance use ($\alpha = .96$), emotional support ($\alpha = .84$), instrumental support ($\alpha = .68$), behavioural disengagement ($\alpha = .45$), venting ($\alpha = .61$), positive reframing ($\alpha = .70$), planning ($\alpha = .73$), humour ($\alpha = .81$), acceptance ($\alpha = .62$), religion ($\alpha = .93$), and self-blame ($\alpha = .74$). These reliabilities are consistent with others found in research involving patients with HNC (Llewellyn et al., 2013).

Post-Traumatic Stress Disorder Symptom Scale (PSS-SR)

The PTSD Symptom Scale Self-Report version (PSS-SR) assesses the presence and severity of PTSD symptoms according to DSM-III-R criteria (Foa, Riggs, Dancu, & Rothbaum, 1993). Respondents are asked to answer each item in relation to a single identified traumatic event. Scores can range from 0-51, and scores higher than 13 indicate PTSD. The PSS-SR has satisfactory internal consistency, high test-retest reliability, and good concurrent validity (Foa et al., 1993). The scale had good reliability ($\alpha = .95$). PTSD symptoms were not assessed at diagnosis, as symptoms need to be present for at least 4 weeks in order to detect PTSD caseness.

Analysis

Data were analysed using SPSS version 21. Independent samples t-tests were used to investigate differences in PTSD and HRQL between patients with an early cancer stage (I-II) versus a later cancer stage (III-IV), patients who had surgery versus radiotherapy, and patients who had single modality treatment versus combined modality treatment. Pearson product-moment correlations were used to examine relationships between baseline coping strategies and follow-up PTSD and HRQL. Following this, hierarchical multiple regression analyses were used to examine which coping strategies had the capacity to predict each outcome at 6 month follow-up. Cancer stage and baseline scores

were entered in the first step, and coping strategies correlated with the outcome of interest at $p < .01$ or less were entered in step two (in order to limit the number of variables in each regression model). A 2-sided p -value less than .05 was considered statistically significant. Missing data were addressed using pairwise deletion.

Results

Descriptives

Twelve of 64 patients had scores indicative of PTSD at 6 month follow-up (19%). Age was not significantly correlated with post-traumatic stress or HRQL at diagnosis or follow-up, and there was no significant difference between men and women. There were no significant differences in post-traumatic stress or HRQL (at diagnosis or follow-up) between patients who had surgery and patients who had radiotherapy, and there were also no differences between those who had single modality treatment and those who had combined modality treatment. At diagnosis, patients with an early stage cancer (I-II) reported significantly higher HRQL ($M = 123.67$, $SD = 18.23$) than patients with a later stage cancer (III-IV) ($M = 114.27$, $SD = 21.01$) ($t(89) = 2.21$, $p = .029$). This difference in HRQL remained at 6 months (stage I-II $M = 122.83$, $SD = 17.02$; stage III-IV $M = 108.13$, $SD = 24.15$) ($t(63) = 2.81$, $p = .007$). There was no significant difference between patients with different stages of cancer with respect to post-traumatic stress. No significant difference was observed between patients with HNC and patients with an advanced skin cancer in the head and neck region with respect to post-traumatic stress or HRQL.

Associations between Coping, PTSD, and HRQL

Denial, substance use, behavioural disengagement, venting, and self-blame at diagnosis were significantly correlated with lower HRQL and higher post-traumatic stress at follow-up (see Table 12). Interestingly, the use of humour was also positively correlated with post-traumatic stress scores.

The intercorrelations between these coping strategies revealed some moderate associations. Denial was positively correlated with substance use ($r = .35$, $p < .001$) and self-blame ($r = .24$, $p = .020$). Substance use ($r = .29$, $p = .004$) and venting ($r = .28$, $p = .006$) were also positively correlated with self-blame. No other significant correlations were identified.

Table 12. Associations between patient coping strategies at diagnosis and post-traumatic stress, distress, and HRQL scores 6 months later

Coping Strategy Baseline	Post-Traumatic Stress at 6 months	HRQL at 6 months
Self-Distraction	.22	-.19
Active Coping	-.10	-.02
Denial	.43**	-.37**
Substance Use	.35**	-.49**
Emotional Support	.15	.11
Instrumental Support	.12	-.03
Behavioural disengagement	.42**	-.40**
Venting	.27*	-.27*
Positive Reframing	.03	.19
Planning	.06	-.01
Acceptance	-.07	.10
Religion	.08	-.06
Self-Blame	.53**	-.52**
Humour	.28*	-.01

Note. * $p < .05$, ** $p < .01$

The first regression model presented in Table 13 explained 53% of the variance in patient post-traumatic stress (adjusted $R^2 = 48\%$; $F(6,55) = 10.37$, $p < .001$). Baseline distress scores explained 24% of this variance and coping strategies explained an additional 26%. Denial, behavioural disengagement, and self-blame each made a unique statistically significant contribution to the model.

The second regression model presented in Table 13 explained 73% of the variance in HRQL (adjusted $R^2 = 71\%$; $F(7,49) = 17.74$, $p < .001$). Baseline HRQL and cancer stage contributed 59% of the variance and the coping variables contributed an additional 14%. Self-blame was the only coping strategy to make a unique statistically significant contribution to the model.

Table 13. Multiple regression analyses predicting PTSD and HRQL at 6 months from baseline variables

	Unstandardised regression coefficient	Standardised regression coefficient (β)	t
PTSD at 6 months			
Step 1			
(Constant)	-5.40		-1.75
Cancer Stage	2.48	.12	1.06
Baseline Distress	0.87	.50	4.43**
Step 2			
(Constant)	-16.73		-4.93**
Cancer Stage	2.19	.10	1.11
Baseline Distress	0.44	.25	2.39*
Denial	1.42	.23	2.26*
Substance Use	0.48	.07	0.63
Behavioural Disengagement	2.47	.25	2.56*
Self-Blame	2.14	.30	2.90**
HRQL at 6 months			
Step 1			
(Constant)	24.40		2.01*
Cancer Stage	-7.41	-.16	-1.86
Baseline HRQL	0.80	.72	8.45**
Step 2			
(Constant)	77.73		5.04**
Cancer Stage	-7.62	-.16	-2.27*
Baseline HRQL	0.59	.53	6.27**
Denial	-1.80	-.13	-1.72
Substance Use	-2.53	-.15	-1.92
Behavioural Disengagement	-1.96	-.09	-1.15
Self-Blame	-4.00	-.25	-3.33**

Note. * $p < .05$, ** $p < .01$

Discussion

This is the first prospective study to demonstrate that coping strategies at diagnosis predict the development of PTSD symptoms in patients with HNC, and one of only few studies to show that coping strategies predict HRQL. Rates of post-traumatic stress were 19% 6 months following diagnosis, which represents a sizeable proportion of patients and is consistent with rates of 12% and 22% shown in previous research (Kangas et al., 2005a; Posluszny et al., 2015). Post-traumatic stress symptoms at 6 months were predicted by self-blame, denial, and behavioural disengagement, even when controlling for general distress, suggesting that the results are not solely attributable to general negative affect.

This research adds to previous literature regarding the effects of denial and avoidant coping in cancer. While some research has found denial to be related to lower levels of distress, other studies have demonstrated a link with lower HRQL (Vos & de Haes, 2007). Few longitudinal studies have been conducted into the relationship between coping and PTSD in cancer. However, research in other patient groups suggests that avoidant coping is linked to more severe PTSD (Otis, Keane, & Kerns, 2003). This may be because avoidance often results in a paradoxical increase in intrusive thoughts about a stressor (Najmi & Wegner, 2008). The correlation between the use of humour and PTSD symptoms found in this study is curious, although consistent with other findings (Aarstad et al., 2008). More research is required to determine if this is a robust association.

The use of self-blame as a coping strategy at diagnosis predicted PTSD symptoms and low HRQL, both of which are new findings in patients with HNC. Previously, a prospective relationship has only been shown between self-blame and depression (Llewellyn et al., 2007b). However, self-blame has been associated with distress in patients with other cancer types (Malcarne, Compas, Epping-Jordan, & Howell, 1995), including lung, breast, and prostate cancer (Else-Quest, LoConte, Schiller, & Hyde, 2009; Houldin, Jacobsen, & Lowery, 1996). The deleterious effects of self-blame on patient psychological wellbeing are likely attributable to negative self-evaluation and increased self-focused attention (Frisch, 1998), each of which have been implicated as precursors for mood disorders (Smith, Ingram, & Roth, 1985), particularly depression.

These results have implications for the development of psychological interventions that aim to address the use of disengagement coping and self-blame at diagnosis in patients with HNC. As part of this, it would be important to introduce routine screening following diagnosis using a brief coping questionnaire. This would enable identification of patients engaging in ineffective coping behaviours

who would most benefit from psychological support. Targeted interventions could then be delivered, involving one or more sessions with a psychologist or nurse specialist, in which patients could be encouraged to replace their coping strategies with more adaptive techniques, such as problem solving, relaxation, goal setting, communication, and the development of support networks.

If psychological interventions are successful at modifying patient coping behaviours they may result in improved HRQL and fewer symptoms of PTSD following HNC treatment. While interventions to improve coping have proven beneficial in patients with other types of cancer (Gaston-Johansson et al., 2000), there is an absence of methodologically sound studies testing psychological interventions for patients with HNC (Semple et al., 2013). Efforts to reduce PTSD symptoms and increase HRQL could have a number of clinical benefits for this group, given well-documented associations linking PTSD and low HRQL to rehospitalisation, disease relapses, symptom intensity, and morbidity and mortality (Cavalcanti-Ribeiro et al., 2012; Mehanna & Morton, 2006).

There are several limitations to this study. First, in order to ensure that we captured patients' subjective understanding of their HRQL it may have been appropriate to also include a global quality of life scale. Second, a limitation of using the Brief COPE is that subscales can have low reliability (Hankins, Foster, Hulbert-Williams, & Breckons, 2013). Finally, PTSD symptoms were assessed at 6 month follow-up only, which prevented investigation of changes in PTSD over time.

In conclusion, this prospective study is the first to demonstrate a link between the use of avoidant coping strategies and self-blame at HNC diagnosis and post-traumatic stress and low HRQL 6 months later. Future research could investigate whether identifying patients engaging in these strategies and providing coping-based psychological interventions can reduce PTSD and improve HRQL.

Chapter 6. Illness Perceptions, Coping, and Post-Traumatic Stress among Caregivers

Preface

The publications presented in previous chapters of this thesis have focused on the way in which illness perceptions and coping are related to the psychological outcomes of *patients* with HNC. Attention is now turned to the caregivers of these patients, and an investigation into whether the CSM also has utility in understanding their psychological responses to HNC is undertaken.

Informal caregivers are often the primary providers of social and emotional support for patients with cancer, and have a large impact on how well patients manage the disease (Stenberg, Ruland, & Miaskowski, 2010). The demands placed on caregivers have been increasing over time as hospitals require shorter patient stays and rely heavily on outpatient services to provide cancer treatment and support (Glajchen, 2004). As a result, caregivers must often assist patients to cope with debilitating side effects of treatment in the home environment. Although the importance of caregivers in the management of cancer is well-recognised (Hodges et al., 2005), there is only a small literature dedicated to understanding the strain and burden they experience, and the physical and psychological impact of the caregiving role is poorly understood (Rhee et al., 2008). Nevertheless, available evidence suggests that caregivers of patients with cancer have high levels of unmet needs (Hileman, Lackey, & Hassanein, 1992), and frequently report cancer-related anxiety, depressive symptoms, and poor overall health (Stenberg et al., 2010).

The experience of psychological distress has been identified as particularly prevalent among caregivers of patients with HNC. Specifically, studies have found that these caregivers report high levels of anxiety and fear of cancer recurrence, which consistently exceed levels documented in both patients and the general population (Longacre et al., 2012). Distress is evident among caregivers even when it cannot be detected in the patients for whom they are providing care (Verdonck-de Leeuw et al., 2007). An investigation of the prevalence of PTSD approximately 4 weeks after HNC diagnosis found that caregivers (all of whom were a partner or spouse of the patient) reported more than two times the rate of PTSD symptoms than that observed among patients (Posluszny et al., 2014). Caregivers have expressed a need for assistance with the management of their distress, conveying a desire for more

information, individual psychological support, and contact with support groups (Baghi et al., 2007; Ross et al., 2010).

The psychological difficulties of individuals caring for patients with HNC suggest that they are strongly impacted by the disease. While many cancer caregivers must contend with alterations in patient functional ability, appearance, capacity to work, sexual functioning, and family and social roles (Nijboer et al., 1998), these issues are particularly pertinent to HNC caregivers. Qualitative research has highlighted that not only must HNC caregivers assist patients to manage difficulties with appetite and eating, loss of basic functions (e.g. speech), facial disfigurement, and a broad number of lifestyle restrictions, but they must also manage their own competing demands, financial strain, and comorbid health problems (Bond et al., 2014; Balfe et al., 2016a). Such difficulties have been found to contribute to the experience of HNC caregiver psychological distress. The witnessing of patient suffering has also been identified as highly challenging by caregivers of patients with cancer (Nijboer et al., 1998). Caregivers of patients with HNC describe the inability to relieve patients of the physical, mental, and emotional pain associated with the disease and treatment as one of the most challenging aspects of their role (Balfe et al., 2016a).

Although research suggests that caregivers must provide complex support to patients with HNC, and that levels of burden and psychological distress are elevated among these individuals, factors that may help to explain variation in caregiver responses to HNC are yet to be identified. In fact, these caregivers are a largely understudied group, and there have been requests for further research to examine their health and wellbeing (Howren et al., 2013), and to identify variables linked to their experience of distress (Longacre et al., 2012). Given the importance of illness perceptions and coping among patients with HNC, it is plausible that these factors may also be associated with the psychological wellbeing of caregivers. As previously mentioned, caregivers have been found to develop their own representations of a patient's illness (e.g. Quinn et al., 2016). According to the CSM, these representations will influence the behaviours caregivers select to cope with the illness, and subsequent health outcomes. Illness perceptions may be of particular significance among caregivers of patients with HNC because of the degree to which they share in the illness experience (Patterson et al., 2013).

Despite evidence that caregiver illness perceptions and coping strategies are related to patient psychological outcomes (Heijmans et al., 1999), including the investigations presented earlier in this

thesis, limited research has explored these variables in relation to caregivers' own wellbeing. Indeed, such relationships are yet to be examined in the context of cancer. However, studies involving caregivers of patients with other chronic illnesses have demonstrated a link between CSM components and caregiver outcomes. For example, illness perceptions (including perceptions of a strong illness identity, many consequences, and low treatment control) and coping strategies (self-blame) were associated with greater distress among 42 relatives of patients with schizophrenia (Fortune, Smith, & Garvey, 2005). Similarly, in a study of caregivers of patients with non-acute stroke, illness perceptions accounted for a greater proportion of variation in caregiver distress than objective indices of patient disability (McClenahan & Weinman, 1998). Discrepancies in patient and caregiver illness perceptions have also been related to higher levels of depression and worry in the partners of patients with chronic plaque psoriasis (Richards et al., 2004).

In light of the absence of studies examining illness perceptions and coping among caregivers of patients with HNC, data from Study 1 were investigated to explore whether these variables may help to explain variation in caregiver distress. Specifically, the contribution of caregiver illness perceptions and coping strategies at diagnosis to PTSD levels 6 months later was considered. Prior to this study, no published research had aimed to identify psychological factors that may contribute to HNC caregiver PTSD, despite evidence that symptoms are prevalent early after patient diagnosis (Posluszny et al., 2014). The longitudinal nature of Study 1 made it possible to identify the prevalence of caregiver PTSD symptoms at a later stage in the disease trajectory, and allowed for insight into the temporal relationships between illness perceptions, coping, and PTSD from time of diagnosis to 6 month follow-up.

Citation

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Abstract

Purpose: There is evidence to suggest that caregivers of patients with HNC are susceptible to PTSD symptoms. The aim of this study was to investigate whether illness perceptions and coping strategies contribute to the development of these symptoms.

Methods: Seventy-eight caregivers completed questionnaires to assess distress, illness perceptions, and coping at diagnosis. Six months later PTSD symptoms were assessed. Correlation and regression analyses were performed to examine relationships between illness perceptions and coping at diagnosis and PTSD symptoms at 6 months in 48 caregivers.

Results: Nineteen percent of caregivers met criteria for estimated PTSD caseness at 6 month follow-up. A regression analysis demonstrated that caregiver perceptions of low treatment benefit and many cancer symptoms, as well as use of avoidant coping techniques, predicted subsequent PTSD.

Conclusions: This preliminary study suggests that caregivers who have perceptions of low benefit from treatment and many patient symptoms, and those using avoidant coping strategies, are at increased risk of experiencing symptoms of PTSD. Psychological interventions that target illness perceptions and coping may help to reduce the prevalence of PTSD in caregivers of patients with HNC.

Background

Head and neck cancer places a heavy burden on both patients and their caregivers. The disease and its treatment are not only associated with complex psychosocial challenges but also with functional difficulties related to speaking, swallowing, and eating (Howren et al., 2013). Patients often require assistance from family members and close friends, who are commonly known as informal or family caregivers (Longacre et al., 2012). From diagnosis, through to treatment and recovery, informal caregivers of patients with HNC serve as a source of both informational and emotional support, and assist patients with self-care, medical tasks, and financial matters (Ross et al., 2010). Consequently, they must often contend with a number of stressors, including changes in family roles, disruptions to daily routines, and physical, emotional, and financial strain (Donnelly et al., 2008).

Despite research to suggest that patients with HNC rely heavily on their caregivers for support, few studies have investigated caregiver psychological adjustment (Howren et al., 2013). A review of available evidence suggests that caregivers report higher levels of anxiety than the general population, as well as the patients for whom they are caring (Longacre et al., 2012). Caregivers of patients with HNC also report low mood and fear of cancer recurrence (Hodges & Humphris, 2009). Moreover, recent research has established that spouses of patients with HNC report high levels of PTSD symptoms at diagnosis (Posluszny et al., 2014). Twenty-nine percent of spouses met criteria for estimated PTSD caseness in comparison to 11% of patients.

Post-traumatic stress disorder is a psychiatric condition that may develop after exposure to a traumatic event. In order for an individual to receive a PTSD diagnosis, they must experience symptoms from each of four distinct categories. These include symptoms characterised by re-experiencing the traumatic event (such as intrusive memories, dreams, or flashbacks), avoidance, heightened arousal, and negative changes in cognitions and mood (APA, 1994). Symptoms must last for a period of at least 4 weeks and cause clinically significant distress or impairment in important areas of functioning. A diagnosis of cancer is recognised in the DSM-IV as a traumatic event capable of eliciting PTSD (APA, 1994). Post-traumatic stress disorder can develop not only in individuals directly affected by a traumatic event, but also in those who witness such an event. Therefore, HNC caregivers are susceptible to PTSD. They must contend with the shock of a life-threatening and potentially debilitating diagnosis and the chronic stress associated with caregiving that this entails, as well as the threat of losing a loved one.

While several factors have been shown to contribute to the psychological wellbeing of patients with HNC (Howren et al., 2013), this is not the case for their caregivers. There have been several calls for more research in this area (Ross et al., 2010) given associations between caregiver psychological wellbeing, quality of life, and physical health (Schulz et al., 1997). There are mixed results regarding the influence of gender, education level, and age on HNC caregiver psychological wellbeing (Longacre et al., 2012), but available research suggests that psychological distress is significantly associated with a disrupted life schedule (Verdonck-de Leeuw et al., 2007), caregiver strain (Donnelly et al., 2008), and greater time spent caregiving (Ross et al., 2010). Poor psychological health is also associated with levels of perceived caregiving burden and such burden is positively related to patient needs and treatment-related factors (Chen et al., 2009). Caregivers report higher levels of perceived burden and strain at 2-6 months post-diagnosis, compared to later in the disease trajectory (Blood et al., 1994). Only one study has identified factors that are associated with the experience of PTSD symptoms in HNC caregivers and this found that depression and anxiety, as well as perceptions of disease threat, were associated with a greater number of symptoms (Posluszny et al., 2014).

Caregivers' perceptions of HNC and the strategies that they use to cope may also contribute to their psychological wellbeing, including the experience of PTSD. Leventhal and colleagues (1980) developed the CSM, which proposes that when individuals are confronted with an illness - such as HNC - they form a representation of that illness that guides the way in which they cope. Coping strategies are thought to mediate the relationship between illness representations and health outcomes, including psychological distress. Illness representations are characterised by perceptions of illness duration, identity (illness label and symptoms), causes, consequences, emotional impact, how the illness may be cured or controlled, and illness coherence, or understanding (Moss-Morris et al., 2002).

Illness perceptions and coping strategies have been found to explain between 35% and 49% of the variance in the psychological distress of those caring for patients with oesophageal cancer (Dempster et al., 2011c). Illness perceptions explained the greatest proportion of this variance, particularly perceptions of consequences, personal control, and understanding. Coping strategies are also important. Caregivers of patients with HNC who engage in a passive coping style are more likely to experience psychological distress (Verdonck-de Leeuw et al., 2011). Research in caregivers of patients with other types of cancer has found the use of avoidant coping strategies to be associated with poor physical and psychological health (e.g. Kershaw et al., 2004).

These findings suggest that illness perceptions and coping may have the capacity to predict variation in the PTSD symptoms that have recently been documented in caregivers of patients with HNC. The aim of this exploratory study was to investigate caregiver post-traumatic stress 6 months after HNC diagnosis, and to examine associations with caregiver illness perceptions and coping strategies. Based on the results of previous studies and Leventhal's CSM, it was hypothesised that: 1) negative illness perceptions of HNC at diagnosis (severe consequences, long timeline, low personal and treatment control, strong illness identity, poor understanding, and high concern and emotional impact) would be associated with more PTSD symptoms 6 months later, 2) use of avoidant coping at diagnosis would be associated with more PTSD symptoms 6 months later, and 3) negative illness perceptions and avoidant coping strategies at diagnosis would predict variation in PTSD symptoms at 6 months in a regression model.

Methods

Participants

Participants comprised a consecutive sample of individuals caring for a patient diagnosed with a primary epithelial head and neck cancer (carcinoma in the pharynx, larynx, oral cavity, sinonasal cavity), or an advanced (metastatic) cutaneous squamous cell carcinoma of the head and neck (cSCCHN). Caregivers were recruited from the head and neck outpatient clinic at Auckland City Hospital, New Zealand, between February and October 2013. Eligibility criteria included attendance at the clinic with a patient who had been diagnosed within 3 weeks prior, having a close relationship with the patient (i.e. spouse, family member, close friend, or formal caregiver), and the ability to speak and read English. Individuals were excluded if they were caring for a patient to be treated with palliative intent in an effort to increase the response rate at 6 month follow-up. Relatedly, caregivers were excluded if they had any condition that might interfere with participation such as cognitive impairment, physical disability, or psychiatric illness. Participant characteristics are presented in Table 14.



Table 14. Characteristics of participants at diagnosis and 6 month follow-up

	Diagnosis (<i>n</i> = 78)	Follow-Up (<i>n</i> = 48)
Gender		
Male	16 (20%)	7 (15%)
Female	62 (80%)	41 (85%)
Ethnicity		
New Zealand European	54 (69%)	39 (81%)
Māori	9 (12%)	3 (6%)
Other	15 (19%)	6 (13%)
Education		
Primary School	1 (1%)	0 (0%)
Secondary School (Partial)	23 (30%)	24 (50%)
Secondary School (Complete)	8 (10%)	4 (8%)
Technical or Trade Certificate	12 (15%)	5 (11%)
University Degree	34 (44%)	15 (31%)
Marital Status		
Single	5 (6%)	2 (4%)
Married	66 (85%)	42 (88%)
Divorced	6 (8%)	4 (8%)
Widowed	1 (1%)	0 (0%)
Smoking Status		
Yes	6 (8%)	3 (6%)
No	72 (92%)	45 (94%)
Type of Patient Cancer		
HNC	66 (85%)	41 (85%)
cSCCHN	12 (15%)	7 (15%)
Stage of Patient Cancer		
I-II	29 (37%)	18 (38%)
III-IV	49 (63%)	30 (62%)
Patient Primary Treatment		
Surgery	22 (28%)	16 (33%)
Radiotherapy	56 (72%)	32 (67%)
Caregiver Type		
Spouse/Partner	45 (58%)	30 (63%)
Child (Son or Daughter)	17 (22%)	11 (23%)
Other Family Member	10 (13%)	2 (4%)
Close Friend	5 (6%)	4 (8%)
Formal Caregiver	1 (1%)	1 (2%)

Note. HNC = head and neck cancer; cSCCHN = cutaneous squamous cell carcinoma of the head and neck

Seventy-eight caregivers completed questionnaire booklets at diagnosis. Between diagnosis and follow-up, 11 patients died. Caregivers of these individuals were not contacted at 6 month follow-up as on-going participation was considered to have potential to cause distress. Of the remaining 67 participants, 48 returned the follow-up questionnaires (72% response rate). Reasons for not returning the follow-up questionnaires included: not wanting to complete it for a second time (*n* = 7), issues with the mailing system (*n* = 3), being non-contactable (*n* = 7), and no longer residing in New Zealand (*n* = 2). Participants who did not return the questionnaires did not significantly differ to those who did with respect to medical or demographic characteristics, general distress, or coping at baseline. However,

one difference in illness perceptions was noted. Caregivers who did not complete the follow-up questionnaires perceived more consequences at diagnosis than those who did, $t(78) = -2.024$, $p = .05$.

Power Analysis

Previous research found that perceptions of threat held by spouses of patients with HNC were significantly related to their PTSD symptoms, representative of a medium effect size ($r = .38$) (Posluszny et al., 2014). G-power software (Faul et al., 2007) indicated that a sample of 39 caregivers would be needed to detect a similar effect (setting power at .80 and alpha at .05) using correlation analyses.

Procedure

Approval for the study was obtained from the University of Auckland Human Participants Ethics Committee and the Auckland District Health Board Research Review Committee. Participants were approached about the study while attending the outpatient clinic and those interested provided written informed consent. Following this, participants completed a booklet of questionnaires designed to assess illness perceptions, coping, and distress symptoms. The same questionnaire booklets were posted out for participants to complete again 6 months later, in addition to a questionnaire assessing symptoms of PTSD. Illness perceptions and coping strategies were the independent variables in this investigation, while PTSD symptoms were the primary outcome.

Measures

Caregiver Brief Illness Perception Questionnaire

The Brief-IPQ is a validated self-report questionnaire designed to assess cognitive and emotional representations of illness (Broadbent et al., 2006). Six items assess cognitive representations (consequences, timeline, personal control, treatment control, causes, and identity), two items assess emotional representations (concern and emotions), and one item assesses illness coherence. All items are rated on a 10-point scale, with higher scores representing stronger perceptions. Items were re-worded in order to assess caregiver perceptions of patients' illness, a technique that has been used previously (Broadbent et al., 2009a). Regarding perceptions of consequences and control, caregivers were required to rate their perceptions with respect to both the

patient and their own life. Examples include 'How much do you think your family member's head and neck cancer affects *his/her* life?' and 'How much does your family member's head and neck cancer affect *your* life?'

Brief COPE

The Brief COPE is a questionnaire consisting of 28 items that are designed to assess 14 conceptually different styles of coping (Carver, 1997). For each item respondents rate the degree to which they have been engaging in a particular behaviour on a 4-point scale. The Brief COPE has demonstrated good validity and test-retest reliability, as well as adequate internal consistency in caregiver populations (e.g. Cooper et al., 2008). Coping behaviours assessed include self-distraction ($\alpha = .65$), active coping ($\alpha = .62$), denial ($\alpha = .75$), substance use ($\alpha = .91$), use of emotional support ($\alpha = .85$), use of instrumental support ($\alpha = .79$), behavioural disengagement ($\alpha = .13$), venting ($\alpha = .59$), positive reframing ($\alpha = .81$), planning ($\alpha = .72$), humour ($\alpha = .73$), acceptance ($\alpha = .74$), religion ($\alpha = .90$), and self-blame ($\alpha = .48$).

General Health Questionnaire-12 (GHQ-12)

The GHQ-12 consists of 12 items used to identify presence of distress, in both clinical and general populations (Goldberg, 1992). Items assess inability to carry out normal functions in addition to the appearance of new and distressing experiences. Respondents make ratings on a 4-point scale. Scores greater than 15 on the GHQ-12 are indicative of clinically significant psychological distress. The questionnaire has demonstrated good internal consistency and test-retest reliability (Goldberg, 1992), and has been identified as a valid and sensitive measure for detecting anxiety and depression in a diverse sample of family caregivers (Cuellar-Flores, Sanchez-Lopez, Liminana-Gras, Colodro-Conde, 2014). Cronbach's alpha of the scale in this study was .81.

Post-Traumatic Stress Disorder Symptom Scale (PSS-SR)

The PSS-SR is a 17-item self-report questionnaire designed to measure symptoms of PTSD (Foa et al., 1993). Respondents rate the frequency or severity of each symptom in the past week, with 0 representing 'not at all' and 3 representing '3-5 times a week/very much'. Scores higher than 13 on the PSS-SR are indicative of PTSD caseness. The questionnaire has good concurrent validity, high test-retest reliability, and satisfactory internal consistency (Foa et al., 1993). In the present study,

caregivers were asked about their symptoms in relation to the specific event of a close other being diagnosed with HNC. The scale had excellent reliability ($\alpha = .93$).

Analysis

Data were analysed using SPSS version 21. Descriptive statistics were performed to determine the percentage of participants meeting PTSD caseness. Independent t-tests and ANOVAs were conducted to investigate the impact of demographic and medical characteristics (caregiver type, gender, ethnicity, education, marital status, patient cancer type, cancer stage, and treatment) on caregiver PTSD symptoms. Pearson's correlation coefficients and hierarchical multiple regression analysis were used to investigate relationships between illness perceptions and coping at diagnosis and symptoms of PTSD 6 months later. Each perception and coping strategy reflects a unique construct and, therefore, each was investigated individually. For the regression model, baseline distress scores were entered in the first step to control for their potential confounding influence. Following this, baseline illness perceptions and coping strategies significantly correlated with PTSD scores were entered (in order to limit the number of variables in the model). Missing data were addressed using the method of pairwise deletion. Although many correlations were conducted, Bonferroni corrections were not applied given evidence that this approach can increase Type 2 error (Perneger, 1998). Instead, exact p -values are provided for transparency.

Results

Descriptives

Nine of the 48 caregivers (19%) met criteria for PTSD caseness at 6 month follow-up based on scores on the PSS-SR ($Range = 31$), and 6 (13%) met criteria for clinically significant distress at this time point based on GHQ-12 scores ($Range = 22$). This compares to 20 of the 78 caregivers (26%) with clinically significant distress symptoms at diagnosis ($Range = 25$). There was a significant change in average distress scores over time ($t(42) = 3.78, p < .001$), with greater mean distress at diagnosis ($M = 13.80, SD = 4.99$) than 6 months later ($M = 10.67, SD = 5.58$).

There was no significant difference in PTSD scores between different types of caregivers, including spouses/partners, children, other family members (e.g. in-laws, grandchildren), and non-family members (e.g. close friends) ($p = .52$). Caregiver age was not significantly correlated with PTSD

scores ($p = .56$), and no significant difference in this outcome was observed between men and women ($p = .79$). There were also no significant differences in caregiver PTSD with respect to ethnicity ($p = .30$), education ($p = .57$), or marital status ($p = .81$). Finally, there was no significant difference in PTSD scores between individuals caring for patients with primary epithelial HNC compared to cSCCHN ($p = .89$), no significant difference in these scores between individuals caring for patients with an early stage tumour (I-II) compared to a late stage tumour (III-IV) ($p = .26$), and no significant difference in these scores between individuals caring for patients who had surgery and those caring for patients who had radiotherapy ($p = .08$).

Correlations between Illness Perceptions and Coping at Diagnosis and PTSD Symptoms at 6 Months

Correlations between caregiver illness perceptions at diagnosis and PTSD symptoms at 6 month follow-up are presented in Table 15. Believing that treatment would be highly effective was associated with significantly lower PTSD scores, while perceiving a strong illness identity (more patient symptoms) was associated with significantly higher PTSD scores. Table 15 also presents correlations between coping strategies at diagnosis and PTSD symptoms 6 months later. Engaging in denial and behavioural disengagement, and using humour to cope, were associated with higher caregiver PTSD. While the internal consistency of the behavioural disengagement subscale was low in this study, both items that comprise the subscale were significantly moderately correlated with PTSD scores.

Table 15. Correlations between illness perceptions and coping at diagnosis and PTSD scores at 6 months

Illness Perceptions/Coping (Diagnosis)	PTSD (6 Months)	p
Illness Perceptions		
Consequences (Patient)	.09	.537
Consequences (Self)	.03	.834
Timeline	.12	.449
Personal Control (Patient)	-.21	.163
Personal Control (Self)	-.20	.186
Treatment Control	-.32	.035
Illness Identity	.35	.018
Concern	.14	.367
Coherence	-.01	.970
Emotional Impact	.24	.113
Coping		
Self-Distraction	.11	.473
Active Coping	.11	.491
Denial	.54	.001
Substance Use	.12	.421
Emotional Support	.06	.676
Instrumental Support	.13	.385
Behavioural Disengagement	.47	.001
Venting	.18	.227
Positive Reframing	.04	.797
Planning	.16	.298
Humour	.36	.016
Acceptance	-.03	.833
Religion	.13	.374
Self-Blame	.23	.119

Regression Analysis

The contribution of illness perceptions and coping at baseline to PTSD scores at 6 months was tested in a regression model, after first controlling for baseline distress scores (see Table 16). Baseline illness perceptions and coping strategies that were significantly bivariately correlated with PTSD were added to the model, including treatment control, illness identity, denial, behavioural disengagement, and humour.

The overall model explained 68% of the variance in caregiver PTSD scores (adjusted $R^2 = 63\%$; $F(6,38) = 13.51$, $p < .001$). Baseline distress contributed 29% of this variance and illness perceptions (treatment control and identity) and coping strategies (denial, behavioural disengagement, and humour) explained an additional 39%. Each predictor made a statistically significant unique

contribution to the regression model. These results were found even when controlling for patient treatment type (surgery versus radiotherapy) (adjusted $R^2 = 64\%$; $F(7,36) = 11.81$, $p < .001$). Results also remained when excluding the only formal caregiver (adjusted $R^2 = 68\%$; $F(6,37) = 16.33$, $p < .001$) and when considering the impact of disease severity by excluding caregivers of patients with cSCCHN (adjusted $R^2 = 58\%$; $F(6, 30) = 9.21$, $p < .001$).

Table 16. Multiple regression analysis demonstrating the contribution of illness perceptions and coping strategies at diagnosis to caregiver PTSD

	Unstandardised regression coefficient	Standardised regression coefficient	t	p
Step 1				
(Constant)	-5.89		-1.74	.089
Baseline Distress	1.01	.54	4.17	.000
Step 2				
(Constant)	-11.39		-2.54	.015
Baseline Distress	0.49	.26	2.44	.020
Treatment Control	-1.05	-.28	-2.99	.005
Illness Identity	0.73	.24	2.59	.014
Denial	2.10	.31	3.16	.003
Behavioural Disengagement	2.46	.22	2.15	.038
Humour	1.97	.28	2.98	.005

Discussion

This preliminary prospective study is the first to demonstrate that illness perceptions and coping strategies contribute to the experience of PTSD symptoms in individuals caring for patients with HNC. Results showed that 19% of caregivers met criteria for estimated PTSD caseness 6 months after HNC diagnosis. This rate is slightly lower than the 29% reported in HNC caregivers between four and 16 weeks after HNC diagnosis (Posluszny et al., 2014), an earlier time frame. The presence of PTSD symptoms at 6 months is consistent with the growing literature demonstrating high rates of psychological distress in HNC caregivers across the disease trajectory (Ross et al., 2010), as well as in caregivers of patients with other cancer types (Mazzotti et al., 2013; Rhee et al., 2008).

After controlling for distress scores, illness perceptions at diagnosis were related to caregiver PTSD at 6 month follow-up. Specifically, caregivers who perceived little benefit from treatment and a strong illness identity (many patient symptoms) at diagnosis were more likely to report PTSD symptoms 6 months later. It is perhaps not surprising that those caring for patients experiencing more symptoms report greater PTSD, as this is likely to entail greater caring demands and, in turn, greater stress. Perceptions of a strong illness identity have been found to predict worse functioning and worse global health in patients with HNC (Scharloo et al., 2010), as well as psychological distress in other patient groups (Arran, Craufurd, & Simpson, 2014; Knibb & Horton, 2008), which may influence caregiver psychological health. The relationship between perceptions of treatment control and PTSD symptoms is more interesting and suggests that having less belief in the benefits of treatment may have implications for caregiver wellbeing. While research has not previously established the predictive power of treatment control perceptions in caregivers, low perceptions of curability have been associated with both depression and anxiety in patients with cancer (Mazzotti, Sebastiani, & Marchetti, 2012). It may be that when individuals have low belief in the effectiveness of treatment, they develop a sense of hopelessness that increases their susceptibility to symptoms of PTSD.

Caregivers who used denial and/or behavioural disengagement at diagnosis had higher PTSD scores 6 months later. Both denial and behavioural disengagement are avoidant coping strategies characterised by behaviours that promote escape from stressful situations and the negative emotions that these can cause (Carver & Connor-Smith, 2010). While no previous research has examined the relationship between coping and PTSD symptoms among cancer caregivers, there is a large evidence base linking the use of avoidant coping with psychological distress in these individuals (Baider, Koch,

Esacson, Kaplan De-Nour, & 1998; Manne & Glassman, 2000; Rodrigue & Hoffman, 1994), including those caring for patients with HNC. Caregivers who spend more time diverting their thinking away from oesophageal cancer report more symptoms of both depression and anxiety (Dempster et al., 2011c). Furthermore, research investigating avoidant coping and PTSD in other groups has found that the use of avoidant coping strategies prevents recovery from the disorder, and is associated with increased symptom severity over time (Badour, Blonigen, Boden, Feldner, & Bonn-Miller, 2012; Pineles et al., 2011). This is likely because avoidant coping strategies prevent anything from being done to actively manage a stressor, and can result in a paradoxical increase in intrusive thoughts (Carver & Connor-Smith, 2010). However, it is acknowledged that avoidant coping behaviours have significant overlap with the symptoms of PTSD.

The use of humour at diagnosis also predicted future PTSD. This is an unexpected finding; other research in caregivers has found the use of humour to predict greater subjective feelings of satisfaction and rewards associated with caregiving (Parveen & Morrison, 2012). It may be that the use of humour is a method of avoiding the situation at hand, although more research is needed to determine if this effect is robust.

There are several limitations to this study. First, the sample of caregivers is small, particularly at 6 month follow-up. This limited the number of predictors that could be included in a regression model and reduced power to detect significant effects. The small sample may also have contributed to the high percentage of variance explained by illness perception and coping variables; future research in larger samples will likely moderate this degree of variation. Second, the behavioural disengagement subscale of the Brief COPE had low internal consistency, in line with previous research that has found the reliability of the questionnaire subscales to be highly variable (Llewellyn et al., 2013). Third, caregivers were a diverse sample (consisting primarily of spouses but also family members and friends). Fourth, a number of individuals caring for patients with metastatic skin cancer in the head and neck region were included in the study because they are representative of many patients at the clinic. These patients are likely to have different care requirements to those with HNC. However, no difference in PTSD scores was observed between caregivers of different patients. Furthermore, illness perceptions and coping continued to contribute to PTSD when excluding caregivers of skin cancer patients from the analysis. Finally, a self-report measure was used to assess caregiver PTSD symptoms. Although the PSS-SR is a widely used and validated questionnaire, the comprehensive

Structured Clinical Interview for DSM-IV disorders is recommended to determine the presence of PTSD (Foa & Yadin, 2011).

Studies that utilise large, homogenous samples of HNC caregivers and that corroborate self-report results with those from clinical interviews are an important avenue for future research. It is also important to explore further predictors of caregiver PTSD, such as the potential impact that clinician interactions can have on this outcome. It may be that consultants and multidisciplinary team members differentially influence caregiver illness perceptions and coping strategies by means of their communication style and relationship with the caregiver.

This study has important implications. The results corroborate previous findings that clinicians need to be aware of PTSD symptoms in not only HNC patients but also their caregivers (Posluszny et al., 2014). This is particularly important in light of evidence that caregiver distress influences patient outcomes (Northouse, Williams, Given, & McCorkle, 2012). Furthermore, our study has identified factors that may contribute to the high rates of PTSD in HNC caregivers – namely, general distress, perceptions that treatment is not very helpful, perceptions that the patient has many severe symptoms, and avoidant coping. Psychological interventions that are designed to improve caregiver distress and illness perceptions, and reduce the use of maladaptive coping strategies at diagnosis, may help to reduce rates of caregiver PTSD. While few studies have tested psychological interventions for individuals affected by HNC, available evidence suggests that they have potential to reduce patient distress (Lockett, Britton, Clover, & Rankin, 2011), including symptoms of PTSD (Kangas et al., 2013). The present findings suggest that it is important to include HNC caregivers in psychological interventions, a technique that has proven effective in other patient groups (Broadbent et al., 2009a).

In conclusion, approximately 20% of caregivers reported PTSD symptoms 6 months after HNC diagnosis. Consistent with Leventhal's CSM, perceptions of treatment control and illness identity, and the use of avoidant coping strategies at diagnosis, were associated with an increased number of PTSD symptoms. Future research could investigate the effectiveness of psychological interventions at modifying illness perceptions and coping strategies in order to reduce symptoms of PTSD among caregivers of patients with HNC.

Chapter 7. Psychological Support Needs of Patients and their Caregivers

Preface

The results presented in this thesis, as well as previous research identifying the negative effects on HNC of patient and caregiver psychological wellbeing, suggest that psychological interventions designed to reduce distress and promote adjustment to the disease are needed. Given the relationships between patient and caregiver illness perceptions, coping strategies, and subsequent psychological outcomes, interventions designed to modify these variables may be particularly effective. However, before endeavouring to develop such interventions it is important to consider whether HNC patients and their caregivers perceive a need for psychological support. Studies have not yet identified patient and caregiver perspectives on psychological interventions and the form that these should take. Furthermore, limited research is available regarding the aspects of HNC that patients and their caregivers would most appreciate assistance with, as well as the way in which their support needs change across the disease trajectory.

The majority of studies investigating the needs of individuals affected by HNC have explored satisfaction with information. Results from a qualitative study employing semi-structured interviews suggest that patients undergoing HNC surgery and their caregivers were well-informed about the surgical procedure (Newell, Ziegler, Stafford, & Lewin, 2004). However, participants reported feeling less prepared for the long-term side effects of the treatment and the associated changes in lifestyle that these entailed. The information, support, and advice provided in the months following surgery were also perceived to be inadequate. These findings are consistent with a study demonstrating that laryngectomy patients and their spouses needed more information regarding the implications of treatment for speech and communication (Zeine & Larson, 1999). Specifically, 21% of patients and 29% of spouses were unaware that patients would have no ability to speak following surgery. Other research has found that HNC patients report difficulties understanding their disease and treatment, receive insufficient information about treatment side effects, and are unaware of long-term problems that may influence their capacity for work, physical functioning, and HRQL (Llewellyn, McGurk, & Weinman, 2005; Llewellyn, McGurk, & Weinman, 2006b).

Unmet needs relating to the provision of information may have implications for the psychological wellbeing of patients with HNC. Evidence to support this is provided by a study that found level of satisfaction with information soon after diagnosis predicted depression 6-8 months after treatment among 50 HNC patients (Llewellyn et al., 2006b). Similarly, in a large cross-sectional investigation of 4020 patients with cancer, unmet information needs were prevalent (affecting between 36% and 48% of patients), and low satisfaction with information was related to the experience of depression and anxiety symptoms, as well as reduced HRQL (Faller et al., 2016). The results of these studies suggest that patients with cancer desire further information, and that psychological interventions could incorporate information regarding the consequences of the disease and treatment in order to successfully prepare patients. This may have positive implications for patient psychological health.

Although several studies have examined information needs among patients with HNC, there are few studies that have examined perceived need for other forms of support. Reviews have identified aspects of the disease which patients experience the most difficulty with, including the management of physical symptoms (speech problems, dry mouth and throat, and trouble swallowing), pain, disturbances in psychological wellbeing (worry, anxiety, depression, and fatigue), and social issues (reduced ability relating to social, recreational, and sexual functioning) (de Boer, McCormick, Pruyn, Ryckman, & van den Borne, 1999). Furthermore, patients struggle with disruptions to daily life posed by their symptoms, uncertainty regarding how the disease will impact their future, and a sense of loss due to their diminished capacity to function after treatment (Lang et al., 2013). Patients identify the importance of supportive relationships for managing these challenges, citing practical and emotional support provided by family, close friends, and health care professionals as essential to their recovery.

Despite evidence that patients consider social support important in enhancing their capacity to cope with HNC, research is yet to establish the forms of support that are perceived to be most beneficial, and from which individuals. In fact, few studies have investigated the extent to which social support is associated with positive outcomes in patients with HNC, particularly in comparison to other cancer populations where the advantages associated with support have been consistently documented (e.g. Falagas et al., 2007). Available research involving HNC patients is equivocal regarding the benefits associated with social support and suggests that more, less, and/or different types of support may be required at different stages of the disease trajectory (Howren et al., 2013). More studies are needed to determine which types of support are most appreciated by patients with HNC, and how

these differ to the support that is typically received. Such studies may help to clarify why difficulties with relationships and social functioning are so frequently reported by this patient group (Happ, Roesch, & Kagan, 2004; Mohide, Archibald, Tew, Young, & Haines, 1992), and the forms of support that could help to address this.

In addition to limited research examining social support needs in the context of HNC, there is a dearth of studies investigating patient and caregiver interest in formal psychological support. Given a strong need for information, as well as frequently reported difficulties in the areas of physical, psychological, and social functioning, interventions that aim to address these issues may be perceived as most useful by patients. However, studies have not elicited patient and caregiver perspectives regarding their desire for psychological interventions, or considered the way in which these individuals would like interventions to be provided. There is some evidence that patients with HNC may be less inclined to receive psychological support than patients with other cancer types. One study found that HNC patients less frequently expressed the wish to have contact with psycho-oncologists (and received less psychological support as a result) in comparison to patients with breast, gynaecological, prostate, urologic, gastrointestinal, lung, brain, and other cancers (Singer et al., 2010). Nevertheless, Llewellyn et al. (2006b) found that patients with HNC wanted to have contact with support groups, a finding that has also been documented among the caregivers of these patients (Baghi et al., 2007; Hanly et al., 2016; Nightingale et al., 2016b).

Further research is needed to ascertain the social and psychological support needs of patients with HNC and their caregivers, and how these needs change over time. By understanding these needs we can determine how support may be provided in a way that facilitates patient and caregiver adaptation to HNC. The following paper presents the final results from Study 1, documenting a qualitative analysis of responses to several open-ended questions completed at time of diagnosis and again 6 months later. Questions were designed to elicit patient perspectives on the support they received from caregivers and health care professionals, and caregiver perspectives on the support they provided to patients. Additionally, both patients and caregivers were asked about their interest in formal psychological support.

Citation

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Abstract

Objective: The aim of this study was to explore the psychological support needs of patients with HNC and their caregivers. The appropriate timing, length, format, and content of support sessions were also investigated.

Design: Eighty-three patients with HNC and 73 of their caregivers completed questionnaires at diagnosis. Follow-up questionnaires were mailed to patients 6 months later.

Main Outcome Measures: Free text-comments to open-ended questions in the questionnaires were analysed using an inductive thematic approach, with coding and theme development directed by the content of responses in order to determine psychological support needs at diagnosis and at 6 month follow-up.

Results: Patients described 'just being there', empathy, maintaining normality, and practical support as helpful from family/friends. They desired information, honesty, positivity, and empathy from clinical staff. Formal psychological support was desired by approximately 40% of patients and caregivers, particularly early after diagnosis and during treatment. Most participants desired face-to-face sessions, providing individualised information and coping strategies.

Conclusion: The results of this study suggest that psychological interventions for patients with HNC and their caregivers should be delivered early after diagnosis in face-to-face sessions, presenting honest and factual information about the disease and coping strategies.

Background

Head and neck cancer encompasses cancers arising in the head and neck region, including the nasal cavity, sinuses, lips, mouth, salivary glands, pharynx, and larynx. Approximately 650,000 new cases of HNC are diagnosed every year, with these accounting for 4% of all cancers (Mehanna, Paleri, West, & Nutting, 2010). Treatment for HNC is complex and often requires a combination of surgery, radiotherapy, and chemotherapy. These treatments can be associated with severe and long-lasting facial disfigurement and disruption to essential function (List & Bilir, 2004). For example, changes in the ability to breathe, speak, swallow, and taste are not uncommon and cause patients significant discomfort and distress (Bjorklund et al., 2010; Funk et al., 2012). The challenges posed by HNC treatment have led to the suggestion that HNC is the most psychologically traumatic cancer (Howren et al., 2013). Depression is particularly prevalent in this patient group, affecting between 15% and 50% of patients at any point in the disease trajectory (Bjordal & Kaasa, 1995; Haisfield-Wolfe et al., 2009).

Although the physical and psychological effects of HNC have been well-documented (Lang et al., 2013), few high-quality studies have investigated ways to best manage these effects with psychological interventions (Lockett et al., 2011). A recent review concluded that shortcomings in the design and reporting of psychological interventions for HNC prevent reliable conclusions regarding intervention effectiveness (Semple et al., 2013). Shortcomings include the small number of studies, lack of power, difficulties with comparability between intervention types, and wide divergence in outcome measures. Furthermore, high rates of attrition and low rates of participation in psychological interventions are common (Humphris & Ozakinci, 2008; Ostroff, Ross, Steinglass, Ronis-Tobin, & Singh, 2004).

At present, no research has investigated HNC patients' desire for formal psychological support, or patients' preferences regarding timing, length, structure, and content. By designing interventions that take into account HNC patient preferences and needs, it may be possible to improve their acceptability and efficacy, and improve rates of compliance (Hammerlid et al., 2001). Psychological interventions for patients with HNC may be further improved by taking into account the desires of patients' family and friends, who provide extensive care throughout HNC diagnosis and treatment (Longacre et al., 2012). Interventions are yet to be adapted to incorporate HNC caregivers, despite evidence that they serve as an indispensable source of support for patients (Kagan, Clarke, & Happ, 2005), and that they experience high levels of psychological distress and anxiety (Longacre et al., 2012). Involving

caregivers in psychological interventions may be an effective way of improving both HNC patient and caregiver wellbeing.

There is evidence to suggest that social support, particularly from caregivers, may have positive implications for HNC patient recovery (Howren et al., 2013). The capacity of social support to improve health outcomes can be explained from a stress and coping perspective (Lahey & Cohen, 2000). Briefly, this perspective proposes that social support serves as a buffer to stressful life events, such as HNC diagnosis or treatment, thereby reducing the effects of these events on health. According to Lazarus and Folkman (1984) social support enhances an individual's capacity to cope with stress. Support in the form of assistance that is matched to the demands of a particular stressor is thought to have the greatest benefits for coping (Cohen & McKay, 1984). However, it is not only supportive actions that are important. Perceptions of available social support can also be beneficial, by helping individuals to *appraise* threatening situations as less stressful (Lahey & Cohen, 2000).

Further investigation is required to determine the types of support that are of greatest benefit to HNC patients (Howren et al., 2013) and the extent to which social support provided by caregivers can be enhanced by psychological interventions (List et al., 2002). The aims of the present study were: (1) to explore the social and psychological support needs of patients with HNC and their caregivers, both at diagnosis and again 6 months later, and investigate whether these support needs change over time, (2) to determine whether patients and their caregivers desire formal psychological support, and (3) to investigate the form that such psychological support should take. It is hoped that the results will assist in the design of more acceptable interventions for this group.

Methods

The exploratory nature of this research necessitated a qualitative approach. To this end, a questionnaire containing a number of open-ended questions was developed and administered to participants. This method enabled us to gain the perspectives of a larger number of participants than other qualitative methods would have permitted, in the least time intensive manner. Thematic analysis was adopted in order to identify, analyse, and report themes within the data (Braun & Clarke, 2006). An inductive approach was taken, whereby coding and theme development was directed by the content of responses to open-ended questions.

Participants

Participants were a convenience sample of 83 patients with HNC and 73 of their caregivers recruited from the head and neck outpatient clinic at Auckland City Hospital between February and October 2013. Patients were included if they had received a diagnosis of primary epithelial head and neck cancer (carcinoma in the pharynx, larynx, oral cavity, sinonasal cavity), or an advanced skin cancer in the head and neck region, up to 3 weeks prior to clinic attendance. Patients and their caregivers were excluded if they were unable to speak or read English, had conditions that would interfere with their participation, or if the patient was to receive palliative care. The majority of caregivers were family members: 41 were a spouse or partner (57%), 19 were a son or daughter (26%), one was a grandchild (1%), five were siblings (7%), and two were a son or daughter in-law (3%). Four caregivers were close friends (5%) and one was a formal carer (1%). Participant demographic characteristics are displayed in Table 17.

Table 17. Demographic characteristics of HNC patients and caregivers

	Patients	Caregivers
Age (Mean and SD)	61 (13)	50 (13)
Gender		
Male	62 (75%)	12 (16%)
Female	21 (25%)	61 (84%)
Tumour Stage		
T1-T2	59 (71%)	
T3-T4	24 (29%)	
Ethnicity		
New Zealand European	61 (74%)	52 (71%)
Maori	10 (12%)	8 (11%)
Samoaan	1 (1%)	1 (2%)
Cook Island Maori	2 (2%)	1 (1%)
Chinese	4 (5%)	1 (1%)
Indian	3 (4%)	5 (7%)
Other	2 (2%)	5 (7%)
Smoking Status		
Smoker	16 (19%)	6 (8%)
Non-Smoker	67 (81%)	67 (92%)
Marital Status		
Married	59 (71%)	61 (84%)
Not Married	24 (29%)	12 (16%)

Procedure

Participants were given a questionnaire that contained open-ended questions designed to assess perspectives on social support (including most and least helpful support), and desire for formal psychological support. Example items in patient questionnaires include: 'What kinds of help from your family and friends do you find most useful?'; 'What kinds of psychological support would you find most

useful from the clinical staff involved in your care?' These items were re-worded slightly in order to assess caregiver perspectives e.g. 'What do you think are the most useful kinds of help that you provide to your family member?' A second questionnaire was mailed to participants 6 months later. This contained the same questions completed at the clinic, in addition to several questions about the form that psychological support should take. Examples include: 'When would be the most useful time to receive psychological care?'; 'Where would it be best to receive this care?'; 'How would you like to receive the care?'; 'What kind of content would you most like to cover in sessions designed to provide psychological care?' Sixty-four patients (77%) and 45 caregivers (62%) completed the follow-up. Ethics approval was granted by the University of Auckland Human Participants Ethics Committee.

Analysis

Open-ended responses were analysed using the six phases of thematic analysis outlined by Braun and Clarke (2006). First, questionnaires were read and re-read to increase familiarity with the data. Initial codes (interesting features) in the data were identified and data was collated for each code. Related codes were organised into categories and potential themes. Themes were reviewed in relation to codes and the dataset, to ensure that they reflected an accurate interpretation. Finally, themes were further refined, and relevant extracts were selected. The semantic identification of themes occurred, whereby themes were classified within the explicit or surface meanings of the data (Braun & Clarke, 2006). Initial codes, categories, and potential themes were identified by the first author. These were then checked and confirmed by the senior author.

Results

Social Support (Family and Friends)

At diagnosis, four themes were identified regarding the types of social support that patients found most beneficial, which are listed in Table 18 along with example quotes. Patients reported the importance of having family and friends who could *'just be there'* throughout diagnosis, treatment, and recovery. However, the form of support that was most consistently identified as beneficial was understanding and empathy. Patients expressed a desire to speak with others openly about their feelings and experiences and wished to receive encouragement to do so. Maintaining a sense of normality was identified as another helpful form of support by several patients. There was concern that the disease may change the way in which family members and friends felt and behaved. Finally,



patients wanted to be practically supported by others, particularly with respect to organising appointments, domestic duties, and transport. Each of these themes, with the exception of 'maintaining normality', were also identified by caregivers as the most beneficial types of social support that they provided to patients at diagnosis.

At 6 month follow-up, the same themes were identified in both patient and caregiver responses, with the exception of maintaining normality. This suggests that maintaining normality became less relevant to patients as they confronted HNC and its associated challenges. Instead, the importance of having someone to talk to – *'Being able to sit and talk about the situation'; 'Being able to talk freely about what I am going through'; 'Talking through the treatment'* was emphasised. Caregivers made greater reference to practical support as most useful at this time point – *'Cooking, cleaning, general housework, shopping, collecting meds, transport to/from doctors and appointments, taking phone calls'; 'Looking after kids, keeping housework ticking over, driving to work/appointments, etc.'*, particularly because of the impact of the disease and its treatment on patients' ability to function – *'I am now his voice and often have to communicate with others on his behalf'*.

Table 18. Patient and caregiver responses regarding most helpful support at diagnosis

Themes	Categories	<i>n</i>	Example Quotes (Patients)	<i>n</i>	Example Quotes (Caregivers)
Being There	Providing company	29	“Visiting, caring, meals and company”; “Just being there and talking about it. It is a big support knowing they are all there”; “Just being there”	32	“At the moment it’s just being around and being with him at all these appointments as he has no one else”
	Regular contact		“Being with me – all the time”; “Contact, interest in what is happening”; “Regular phone call from family - all live out of my area. One family member to come and support me when needed”; “Just visits and texts and contact”		“Being there. Little things at the moment, more help as treatment progresses and she becomes more dependent on me”; “Being there whenever required”
Empathy	Understanding	38	“Unconditional understanding and empathy”; “Letting me do what I want within reason. Doing what I ask even if it’s not right for them”	41	“Try to understand her feelings”; “Listening and understanding”; “Social interactions according to the emotions/physical state”
	Listening		“Just listening and putting up with me”; “Letting me talk without me feeling that I have to censor what I say or protect”; “Being able to talk about my cancer – good or bad”		“Listening to his thoughts and fears and talking about them”; “Listening skills, love, time”; “[Being] someone they can unload their concerns to”
Maintaining Normality	Everyday living	14	“Maintain a sense of normality”; “Just making sure things remain the same way – having time with the family and not making an issue over my illness”; “Live normally”; “Day to day life continues and family and friends have made this happen causing less stress in the family”; “Normality wherever possible”	6	“Nothing different to what we do now”; “Keeping things at home as normal as possible”; “Keeping the family running, life as normal as possible”
	Same treatment		“Not making any issue over my illness”; “Treating me the same as before”; “Just be themselves: not let the situation dictate terms of interaction”		“Visit as usual”; “Same routine”
Practical Support	Domestic tasks	20	“My wife taking care of finances and the general running of home”; “Grocery shopping, help with children”	27	“Helping with kids, household, etc. Doing all the little jobs that I’m asked to do”; “Making sure that her domestic situation is taken care of i.e. making meals, chores, etc.”
	Practical care		“Driving me to and from hospital”; “Practical accommodation and transport”; “Organising my appointments and arrangements”		“Every day help – bathing, eating, dressing, etc.”

Note. *n* – Number of participants who commented on a theme

Social Support (Health Care Professionals)

Patient responses regarding the type of support they considered most helpful from clinical staff differed to their responses regarding support from family and friends. At diagnosis, four themes emerged: 1) information ($n = 16$); 2) honesty ($n = 14$); 3) positivity ($n = 6$); and 4) empathy ($n = 14$). Patients reported needing information in order to prepare for what was ahead – *‘Information about what to expect and how/where to access support materials’*; *‘Being made aware of what is happening – like how and when?’*. They were adamant that this information should be honest, fully disclosing their prognosis and the likely effects of treatment – *‘Give honest and straight up answers or information’*; *‘Full disclosure about my condition’*; *‘More explanations about what is ahead and quicker results. We’ve had very conflicting reports’*. However, they also expressed a desire for clinical staff to take *‘a positive approach to what [was] happening’* and remain *‘optimistic’*. Finally, patients wanted clinical staff to express empathy – *‘Finding out what is important to me. I have feelings and opinions that are important to me’*, requesting that they *‘be present, clear, and loving in their communication’*.

The above themes also emerged in the responses of caregivers, with the exception of *‘positivity’*. Caregivers requested information that could improve their understanding of the situation and prepare them for the future ($n = 15$) – *‘Just a clear and direct prediction of the future’*; *‘Providing clear information as to the diagnosis and prognosis.’* Like patients, they too stressed the importance of honesty ($n = 6$) – *‘Truthful discussion of the situation and plans for treatment. Full truth – no beating around the bush’*. Caregivers also considered empathy from clinical staff an essential aspect of patient care ($n = 20$). In particular, they felt it important that staff respected the individuality of the patient, as well as their worries and concerns – *‘Being sensitive and caring, aware of him as an individual with feelings’*; *‘Someone who understands what she is going through to ease the worries/fear’*.

The same themes were identified at 6 month follow-up, although caregivers also identified the importance of positivity at this time point – *‘The positive outcome for him when the healing is over’*; *‘Keeping him positive’* and expressed a desire for more contact with clinical staff – *‘Regular check ins with the same staff member to monitor progress’*; *‘More contact’*.

Desire for Psychological Support

A number of patients chose not to report whether they wished for psychological support at diagnosis ($n = 19$). Of those who did, 29 reported that psychological support would be beneficial (valid percent = 45%). Reasons for wanting this support included to: 1) improve understanding; 2) gain perspective; and 3) develop coping strategies. Patients felt that talking with a psychologist might improve their understanding of HNC and the long-term implications it would have – *'Yes. Because it would help me understand what is going on'*. Patients also thought that doing so might help them to view their situation from a different perspective – *'Yes – objective discussions from an impartial person may assist in seeing things in a different light'*; *'Yes – it will give me a different perspective to what I have of my own.'* Furthermore, patients thought that talking to a professional may help them develop coping strategies that could be used to manage their diagnosis and treatment – *'Probably ... Could help with any necessary coping strategies for future events'*; *'Yes – develop strategies to cope'*.

A number of patients did not want psychological support ($n = 35$). The most frequently reported reason for this was having a large pre-existing network of supportive friends and family who were available to provide assistance whenever needed – *'No. I have 'at present' all the emotional support I require. In [the] future I may require assistance or emotional support outside of my family'*. Some patients reported that they were already coping very well – *'No, I think I am coping well'* and did not see what added benefit psychological support could provide – *'No – can't change what has happened'*.

At diagnosis, 26 caregivers reported that psychological support would be beneficial (40%). Improving understanding was one frequently reported reason for wanting this support (as was the case with patients) – *'Yes, gives the clear perspective of the disease and treatment plan'*; *'Yes. We will know the exact information about the illness and how we can go about it'*. Caregivers also reported that speaking with a professional may be a means for emotional expression – *'Yes – perhaps talking could help you understand the emotions that come up and surface'*. Caregivers felt that it would be particularly helpful to discuss how they were feeling with someone other than the patient *'Yes – just to be able to express fears I cannot express to him'*; *'Yes – frustration of not being able to lead a full life and impatience which I try not to convey'*. For those caregivers not wanting psychological support ($n = 39$), similar sentiments to those of patients were expressed, including already being well-supported by family and friends – *'Right now I feel ok. I have been a support person before, I understand the*

process, and have a supportive network of family and friends; *'No. I have friends and family who are a huge support to both of us'*.

Fewer patients and caregivers reported wanting psychological support at the 6 month follow-up (30% and 33%, respectively). The same reasons for wanting and not wanting support at baseline were identified again by both patients and caregivers. Many of them had made it through the treatment period by using other methods of support to manage, particularly the help of close family and friends – *'No, because I am a strong person and have family supporting me'*; *'No – I have all the support I need'*. Some patients and caregivers mentioned that it would be too late in the disease trajectory for psychological support – *'Too late. I have had to cope over the worst months of my life'*. Nonetheless, both patients and caregivers acknowledged that their responses may have differed if their situation was more serious – *'I suspect my answers would have a very different tone if my wife's cancer was deemed incurable or fatal instead of having an excellent long-term outlook'*, or they had limited support available – *'If I had no support I would need to talk to a psychologist'*.

Form of Psychological Support

A number of patients requested that psychological support be provided early after diagnosis and before the start of treatment ($n = 22$) – *'I think all throughout, mostly before treatment as it is shocking and nerve racking and support here will be useful'*; *'My experience leads me to believe early intervention helps also during treatment itself'*; *'Definitely early after diagnosis'*. Many patients believed that it would be helpful to have this support *during* and *after* treatment ($n = 30$) – *'Continuously from diagnosis, throughout treatment, and thereafter for, say, 12 months for those [who] want to receive this care'*. Caregivers felt that it would be most helpful to receive psychological support before the start of treatment ($n = 25$) – *'Before the start of treatment – so we can be prepared for what's ahead of us'*; *'Before to fully prepare them for what they are facing'*. While a number of caregivers felt that psychological support would be beneficial while the patient was undergoing treatment ($n = 10$) – *'Staged throughout the treatment process'*, some questioned whether this would be appropriate given that *'during treatment your focus shifts to caring for the person and dealing with that'*. Finally, several caregivers felt that psychological support after treatment would be most helpful ($n = 8$) – *'From the start would be great, however after the treatment has finished is a "must do"'*.

Both HNC patients and caregivers demonstrated a slight preference for receiving psychological support in their own homes ($n = 32$ patients, 22 caregivers) – *'At home, easier to let emotions flow'*; *'The ability to visit at home would be good'*. However, many reported that they would be happy to receive psychological support at the hospital ($n = 23$ patients, 16 caregivers) – *'Probably at hospital or clinic'*, and some mentioned that there might be advantages associated with a neutral environment – *'Neutral ground, hospital or office'*; *'Hospital. Need to keep home and hospital separate I think'*.

Most patients and caregivers reported that they would prefer psychological support to be in the form of face-to-face meetings ($n = 40$ patients, 32 caregivers) – *'Face-to-face is the best for me'*; *'It would need to be one on one, face-to-face'*. It was suggested that this format allows for the greatest expression of empathy and mutual understanding – *'Face-to-face – keep the care personal and human'*; *'Face-to-face – personal contact is easier in terms of relationship building'*. However, some participants reported that they would like support to be provided in a wide array of formats, including meetings, phone calls, brochures, and online information ($n = 10$ patients, 10 caregivers) – *'Face-to-face meetings; 24/7 phone access; information on the internet'*; *'Face-to-face. Factual information in brochure or online'*.

While the majority of patients and caregivers were in favour of either 1-3 or 4-6 meetings ($n = 29$ patients, 25 caregivers) some were in favour of long-term psychological support ($n = 6$ patients, 9 caregivers) – *'11 or more'*; *'Perhaps 10 – 1 per month from the time of diagnosis'*. Many participants stated that there would be individual differences in the number of meetings desired, stressing the importance of leaving this up to the person receiving support – *'However many it would take for the individual'*; *'As many as it takes. Everybody is different'*; and considering their level of need – *'As many as needed'*; *'I guess that would depend on individual needs'*.

The majority of HNC patients reported that they would prefer individual meetings, involving just themselves or themselves and a family member ($n = 35$) – *'Just me and a family member'*; *'One on one situation. Group therapy may work for some but not my style or way thanks'*. However, a number of patients reported they would like a combination of both individual and group sessions ($n = 17$) – *'Individual sessions to start off with, then a group session'*, with group sessions taking place later in the disease trajectory – *'After treatment finished with a group'*; *'Share experience with other people, so you know you are not alone, everyone will have the same problems'*. Caregivers were in support of group sessions ($n = 16$) – *'Group, great to meet others, lifts your spirits being with people and not alone'*,

although a large number also reported that individual meetings would be beneficial ($n = 19$) –

'Individual. But I also see the benefit of [a] group situation as others may have good ways to cope and support'.

Both patients and caregivers' ideas about the content they would most like to cover centred around three main themes. These themes are listed in Table 19 along with example quotes. First, they expressed a desire for information about HNC and its treatment, in order to best prepare themselves for the future. Second, they wanted to be able to express their emotions, particularly their fears and concerns relating to the disease. Finally, both patients and caregivers requested coping strategies. Patients were particularly interested in techniques that might help them to cope with side effects of treatment and the distress that these can cause, while caregivers requested techniques to reduce stress.

Table 19. Patient and caregiver responses regarding content of sessions designed to provide psychological support

Themes	Categories	<i>n</i>	Example Quotes (Patients)	<i>n</i>	Examples Quotes (Caregivers)
Information	Information about HNC	20	“Information specific to disease, experiences of others in similar situation”; “Basic responses physically, to treatment and psychological effects/responses to that, and support strategies for family members”	21	“Effect of the cancer, treatment, outcomes, follow-ups and support available plus long-term outlook”; “How long before complete recovery and possible hold ups, setbacks, opinions, etc.”
	What to expect (treatment and recovery)		“Effect of particular cancer and what to expect further into treatment”; “What to expect, how to cope with problems that may arise, possible eventual outcome”		“Stages of treatment, emotional changes, physical changes, eating challenges, how the illness affects all family members”; “What to expect – how patients are likely to respond and what they may experience emotionally”
Emotional Expression	Expressing emotion	14	“Expressing feelings (how to), the need to protect others from personal fears, letting down one’s guard”; “The emotional roller coaster. How cancer can affect you and your family”	8	“A place to express feelings”; “Expression of emotions”
	Discussing personal fears and concerns		“Dealing with the shock of diagnosis and the disfigurement involved”; “Personal feelings and fears”		“Whatever is most likely to come up because of the trauma involved. Stirred up emotions and life changing ‘threats’”
Coping Strategies	Coping with treatment	12	“How to cope with the side effects of treatment”	14	
	Coping with distress		“Dealing with the cancer or learning how to deal with it so that it does not consume you 24/7”; “How to cope with stress, worry about family”		“Tools to deal with the practicalities and emotions that occur”; “How to cope with stress”; “How to support someone who is stressed and very depressed when you are feeling the same way. Positive ways of coping. How family can help”; “Keeping positive. Ways to relax. Things to do to keep your own spirits up”

Note. *n* – Number of participants who commented on a theme

Patients and caregivers had a number of other suggestions regarding how illness-related stress might best be managed. These suggestions are listed in Table 20 in addition to example quotes. Several patients mentioned that improving communication among members of the HNC multidisciplinary team was vital to ensuring their physical and psychological wellbeing. Patients also wanted information to be clearly communicated to them, particularly in the early stages of the disease. Both patients and caregivers emphasised that by having information they would be in a better position to cope with HNC and its consequences:

'Stress is best managed with knowledge - the more a patient knows the better (there will be individual exceptions). Knowledge of my cancer, the surgical process, and the post-op and recovery knowledge was parsed out to me over time. I got the feeling that, from surgeon to nursing staff, no one wanted to "overwhelm" me with information when, in fact, I would rather have all of the information up front.'

Patients and caregivers also reported that empathy is a key requirement of all service providers and that more practical assistance may make it easier to manage the disease.

Table 20. Patient and caregiver suggestions regarding how to best manage stress caused by HNC

Themes	Categories	Example Quotes (Patients)	Examples Quotes (Caregivers)
Improved Communication	Communication between multidisciplinary team members	<p>“To have 'wrap around' care, more clear communication between ALL staff involved. Physically and psychologically”;</p> <p>“Improved communication among ALL services, departments, and treatment/care providers”</p>	<p>“Information, information, information. Recipes, foods to avoid, sleeping interruptions, keeping the mouth clean. All this knowledge stops the pressure of trying to find solutions for the problems experienced”</p>
	Communication of information	<p>“I personally found it stressful when I sought answers to questions/issues that I found important, too many people tried to deflect giving answers - passing you off to others - (often not present). Understanding the situation helps develop coping strategies”</p>	
Honest Approach	Frank discussion	<p>“A more open discussion and true facts of treatment and recovery”; “For myself I appreciated the bluntness they gave me at diagnosis. When I left that meeting I had 100% accepted it”</p>	<p>“Full disclosure about all side effects during and POST-treatment, and how long these may last”</p>
Empathy	Understanding and compassion	<p>“Empathy is the key requirement on the part of anyone attempting psychological help. Completely lacking in the medical and hospital staff (except for a few) but the district nurses were wonderful. No wonder so many people are turning to alternative therapies!”; “Perhaps greater respect from ALL providers (plus family and friends) that the patient is physically ill throughout all this. I prefer the word 'person'”</p>	<p>“Retain caring, comforting, genuine staff. From the surgeons, radio/chemo crew, nurses, receptionist, specialists, and after-care. Everybody involved in my husband's care has been so good to me regarding my needs and concerns”; “Treating Dad as a person, not a symptom/illness. Appreciating that he is independent and very capable despite being 88”</p>
Practical Support	Practical assistance	<p>“Practical subjects e.g. employment, participating in society, being financially independent, etc.”</p>	<p>“It would be great [to] have some home support. In our case we only have each other (no other family members in the country) so household doings - cooking and clean environment - was what we missed to be provided to us by someone else”</p>
	Financial support	<p>“Financial, which is zero for me, no financial assistance”</p>	
	Work	<p>“Have the support organisations find suitable work. Government lacks anything along these lines”</p>	

Discussion

This is the first study to investigate HNC patient and caregiver needs for social and psychological support, both at diagnosis and again 6 months later. Findings suggest that patients and their caregivers relied heavily on support from family and friends. Approximately 40% of patients and caregivers desired formal psychological support, particularly at diagnosis. Most wanted this support to be in the form of face-to-face sessions with a psychologist, providing information about what to expect from the disease and strategies that may make it easier to cope. Overall, the data confirm that interventions designed to promote the psychological wellbeing of patients with HNC and their caregivers are needed.

Patients reported that having family and friends who were available to provide empathy was the most helpful form of social support, both at diagnosis and again 6 months later. Such support was identified as useful at reducing feelings of distress, a finding consistent with prior research demonstrating a link between available support at HNC diagnosis and less depressive symptomology 6 months later (de Leeuw et al., 2001). The availability of social support has also been associated with global and condition-specific quality of life in this patient group (Howren et al., 2013; Karnell et al., 2007). A systematic review and meta-synthesis of qualitative studies describing the psychological experience of living with HNC corroborates the importance of social support, with patients utilising their support networks in order to cope both emotionally and practically with the disease (Lang et al., 2013).

Patients emphasised the importance of having close others who could help to maintain a sense of normality at diagnosis. However, this finding no longer emerged at 6 month follow-up. It may be that patients found it increasingly difficult to maintain a sense of normality after being confronted with the challenges associated with HNC treatment (including difficulty breathing, speaking, and swallowing, pain, and disfigurement). Several studies have noted that patients with HNC and their caregivers modify their normal daily routine (both at home and at work) in order to accommodate physical impairments and treatment side effects (Molassiotis & Rogers, 2012; Roing et al., 2007; Semple & McCance, 2010). Caregivers in the present study reported that providing practical support became more important post-treatment, suggesting that they adjusted their support provision to the needs of the patient. According to Lazarus and Folkman (1984), this is likely to confer the greatest benefit for patient coping and subsequent health outcomes.

Different types of support were sought from healthcare professionals. At diagnosis and again at follow-up, patients and caregivers wanted healthcare professionals to provide honest information about the impact of HNC and its treatment, yet in a way that communicated positivity and empathy. This need for information is consistent with a number of studies reporting that patients with HNC have high information needs (Ziegler, Newell, Stafford, & Lewin, 2004), and that current standards of information provision are inadequate. Newell and colleagues (2004) found that many patients undergoing head and neck surgery felt unprepared for the long-term lifestyle changes that occurred and were dissatisfied with the amount of information they had been provided. Other research has found that HNC patients would like more detailed information regarding long-term effects of treatment on ability to work, physical functioning, and HRQL, as well as information about support groups and where to go for financial advice (Llewellyn et al., 2006b).

Previous research with other cancer patient groups has shown that there are high levels of need relating to domains of 'information', 'psychological support' and 'physical and daily living' (Sanson-Fisher et al., 2000). This study adds some specific suggestions for the HNC patient group, particularly with regard to communication and coping strategies. One of the strongest themes regarding the content of formal psychological support was a need for information that was honest, fully disclosing the side effects of treatment and the implications these have for recovery. Several patients mentioned that they felt their health care providers were holding back information, for fear of overwhelming or frightening them about what was ahead. This theme of not disclosing information has not been reported in other research. Furthermore, patients with other cancer types tend to report need relating to different matters. For example, women at risk of breast cancer tend to request assistance with loss, unresolved grief, and relationship problems (Hopwood et al., 1998). The need for honest information is likely to be lower in this group, who typically report high satisfaction with the information that they receive (Mallinger, Griggs, & Shields, 2005), although there is some evidence that they desire more information about where to access psychological support (Mehnert & Koch, 2008). Patients with prostate cancer commonly report need relating to fears about the cancer spreading, concern about the worries of close others, and changes in sexual feelings (Lintz et al., 2003). These patients also report that their needs are being well met in the domain of patient care and support.

Patients and caregivers in the present study reported a need for coping strategies that may make it easier to manage the disease, particularly the side effects of treatment. This is not typically reported by patients with other cancers (Sanson-Fisher et al., 2000), and likely reflects the unique

challenges associated with HNC treatment. Challenges can include, but are not limited to, severe disfigurement and significant disruption to basic functions such as speaking, breathing, and eating (List & Bilir, 2004). Coping strategies to manage these difficulties may be more pertinent to patients with HNC than they are to patients with other types of cancer, where there are not such severe side effects associated with treatment. Study findings demonstrate the importance of tailoring psychological interventions to the needs of specific cancer types.

This is the first study to investigate cancer patients' desires regarding the timing, content, and delivery of formal psychological support. The results have clear implications for the design and development of psychological interventions specifically for patients with HNC. Interventions could provide open and honest information and coping strategies, preferably in face-to-face sessions with a psychologist, delivered at home or in the hospital. While patients and caregivers were open to receiving this support at all stages of the disease trajectory, diagnosis was identified as a time at which psychological support would be particularly beneficial, consistent with previous research findings (Hammerlid et al., 2001; Humphris & Rogers, 2012; Richardson, Lee, & Birchall, 2002). Most patients reported a preference for sessions to be conducted individually, in line with results that HNC patients' desire individualised (one-to-one) cognitive behavioural therapy (Semple, Dunwoody, Sullivan, & Kernohan, 2006).

While psychological interventions conducted to date have endeavoured to provide HNC patients with information (Katz, Irish, & Devins, 2004a) and coping strategies (Duffy et al., 2006), none have successfully been delivered from diagnosis through treatment (a time at which this study found psychological support was needed). Instead, interventions have been conducted post-treatment (e.g. Humphris & Rogers, 2012). Many interventions have involved 2-3 sessions with a health care professional (therapist or nurse) which was the number desired by patients in the present study. However, these have been offered within a limited window of time (e.g. over a 4-week period) making it difficult for patients receiving treatment to attend. Therefore, it is suggested that psychological interventions for patients with HNC need to be highly individualised in terms of the timing of individual sessions, in order to accommodate the unique challenges associated with HNC treatment. It is also important to note that no study to date has investigated the effectiveness of a psychological intervention for those caring for patients with HNC (Howren et al., 2013). The results of the present study suggest that psychological support is desired by HNC caregivers, and that interventions should be designed to include these individuals.

This study has provided insight into the support needs of HNC patients and caregivers across the disease trajectory. Future research could take these findings into consideration when designing psychological interventions for this patient group in an effort to improve their acceptability and efficacy.

Chapter 8. Psychological Interventions

The previous chapters of this thesis have indicated that illness perceptions and coping are related to psychological outcomes in patients with HNC, and preliminary evidence suggests that these factors may also be important to consider in their caregivers. An implication of this is that psychological interventions designed to target ineffective illness perceptions and coping strategies may be capable of improving the psychological wellbeing of individuals affected by HNC. However, few studies have examined psychological interventions in this patient group to date, and none have involved HNC caregivers. This chapter evaluates the psychological interventions that have been investigated in patients with HNC, their efficacy at improving HRQL and reducing psychological distress, and how they might be adapted to involve caregivers. A rationale for testing self-regulatory interventions in patients with HNC, based on the CSM, is also presented.

Psychological Interventions

Both the UK government and the NCCN in the USA advocate screening for psychological distress among all patients with cancer in order to identify those who would benefit from psychological intervention (Semple et al., 2013). While a clear definition of 'psychological intervention' is yet to be established (Hodges et al., 2011), such interventions typically aim to bring about a positive change in psychological wellbeing by modifying an individual's knowledge, thoughts, or behaviours in response to a challenging situation (Holland, 1982). There is a great deal of variability in psychological interventions with respect to theoretical underpinning, complexity, content, length, and method of delivery.

Intervention Types

Research in the 1990s categorised psychological interventions for patients with cancer into four main types: education, cognitive behavioural therapy, individual psychotherapy, and group interventions (Fawzy, Fawzy, Arndt, & Pasnau, 1995). Education interventions (also known as psychoeducation interventions) are used to improve knowledge and reduce uncertainty by providing information about cancer and its treatment, as well as coping strategies and how these may be employed to reduce psychological distress. Cognitive behavioural therapy (CBT) involves identifying and correcting thoughts, feelings, and behaviours that may be contributing to the experience of psychological distress (Beck, 2011). This is achieved using a range of cognitive and behavioural

techniques, such as cognitive restructuring, pleasant activity scheduling, deep breathing, and progressive muscle relaxation. Individual psychotherapy is a less structured form of psychological intervention (Fawzy et al., 1995), where the focus is on helping a patient to manage the distress and disruption caused by cancer by providing support, compassion, and empathy. Finally, group interventions typically involve weekly meetings with other individuals affected by cancer. These meetings are guided by a psychologist or other mental health professional and allow for the sharing of personal experiences and information exchange.

Cognitive behavioural approaches to the management of distress have been modified over time, resulting in a number of new ('third wave') interventions that do not fall into the categories identified above. Examples of such interventions include acceptance and commitment therapy (ACT) and mindfulness-based stress reduction (MBSR). In contrast to more traditional approaches, acceptance and mindfulness-based interventions consider the context of psychological phenomena (Hayes, 2004). Rather than focusing on changing psychological responses to adverse events, the aim of these interventions is to assist individuals with their *conceptualisation* of such responses (Hayes, Luoma, Bond, Masuda, & Lillis, 2006). Specifically, ACT endeavours to increase acceptance of distressing thoughts, beliefs, sensations, and feelings, in order to change behaviour and, consequently, improve quality of life. Individuals are encouraged to engage in exercises aimed at identifying key personal values, translating these values into specific goals, and designing and implementing behaviour changes that will facilitate the accomplishment of goals (Forman et al., 2012). Similarly, mindfulness interventions (including MBSR) promote the development of sustained non-judgemental awareness in the present moment, including continuous attention to sensations, perceptions, affective states, thoughts, and imagery (Grossman, Niemann, Schmidt, & Walach, 2004). Engaging in mindfulness is proposed to promote increased flexibility in coping with both positive and negative life experiences, and to enhance perceptions of control as a result.

Efficacy of Interventions

Several systematic reviews and meta-analyses have concluded that psychological interventions reduce psychological distress and improve HRQL in patients with cancer (Hart et al., 2012; Jacobsen & Jim, 2008; Williams & Dale, 2006). However, most meta-analyses have found heterogeneous effect sizes across trials. This suggests that while some interventions have produced robust positive effects, others have been ineffective at improving patient outcomes (Stanton, 2006).

The majority of studies demonstrating benefit from psychological interventions have involved patients with breast cancer (e.g. Tatrow & Montgomery, 2006). It is important to consider potential variation in intervention effectiveness across different cancer types, where the symptoms, treatment, and quality of life impact for patients can vary dramatically. Research is yet to conclude whether psychological interventions can be of assistance to patients with HNC (Semple et al., 2013), who must contend with unique physical, social, and emotional challenges, and who report the highest rates of emotional distress following diagnosis and treatment (Howren et al., 2013).

Psychological Interventions and Head and Neck Cancer

Psychological interventions for patients with HNC have received limited research attention, particularly in comparison to those developed and tested among patients with other cancers (Luckett et al., 2011). Nevertheless, a broad range of intervention types have been applied in this patient group, including psychoeducation, CBT, group interventions, telehealth interventions and, most recently, mindfulness. Studies examining the impact of these interventions on HNC patient HRQL and psychological wellbeing are described in more detail below.

Psychoeducation

Although psychoeducation is one of the most commonly investigated interventions for patients with HNC, only five studies have been conducted. The majority of these studies have methodological limitations, and their findings have been conflicting with respect to intervention effectiveness. The strongest support for psychoeducation is from a pilot randomised controlled trial (RCT) involving 19 newly diagnosed oral cancer patients who were allocated to receive psychoeducation or standard care (Katz et al., 2004a). The nurse-led intervention was delivered in both verbal and written format and involved two 60-90 minute face-to-face sessions, with the first prior to surgery and the second post-surgery. At 3 months post-discharge, intervention participants demonstrated improved knowledge, less body image disturbance, and less anxiety compared to participants who received standard care.

These findings are consistent with those documented in an earlier pilot study, in which 14 patients and their spouses participated in a week-long psychoeducation programme one year after surgery for HNC (Hammerlid, Persson, Sullivan, & Westin, 1999b). The programme included individual and group education from a range of HNC specialists, and took place at a comprehensive rehabilitation centre. Psychological distress reduced following the programme, and there was a trend towards

improvement with respect to a number of functional domains (including less trouble eating, fewer problems enjoying meals, and reduced dry mouth). However, formal statistical testing was not employed due to the small number of participants. Furthermore, participants self-selected to take part in the programme and no comparison group was used. While participant satisfaction with the programme was high, a number of patients suggested that it may have been of greater benefit had it been provided earlier in the HNC trajectory.

A larger prospective non-randomised study tested the feasibility of the Nuicare programme for patients with HNC (Allison et al., 2004), which is an education and coping skills intervention found to benefit other patients with cancer (Watts & Edgar, 2004). The programme aims to enhance personal control and the use of emotional and instrumental coping responses by providing information on problem solving, relaxation techniques, cognitive coping skills, goal setting, communication, social support, and lifestyle factors. Fifty post-treatment HNC patients self-selected to receive the Nuicare programme in one of three formats: small group, one-to-one, and at home. The home format had the most positive effect on social functioning and fatigue, with significant improvements from pre- to post-intervention. In contrast, the small group and one-to-one formats had the strongest impact on global HRQL, depressive symptoms, and sleep disturbance. These findings suggest that different intervention formats may be employed to target different aspects of HNC patient wellbeing.

Other studies have not found a positive effect of psychoeducation for patients with HNC. A longitudinal case-controlled study compared 52 patients who participated in a psychoeducation support programme designed to improve HRQL with 92 control group participants who received standard care (Peterson, Silander, & Hammerlid, 2003). The programme was delivered by a nurse and dietician who aimed to provide patients with information about HNC and emotional support, throughout and beyond treatment. The programme did not improve patient HRQL. Instead, participants in the control group reported better global HRQL 1 year after diagnosis and reported feeling less ill at 3 year follow-up. Depression and treatment-related side effects remained prevalent in both groups at this time point.

The results of a more recent quasi-experimental study also found no effect of a nurse-led education intervention (van der Meulen, de Leeuw, Gamel, Hafsteinsdottir, 2013). The intervention was provided to post-treatment HNC patients during a discharge interview and compared with standard care. The aim of the intervention was to improve patient satisfaction with information in light of evidence that patients with HNC report difficulty accessing information and feel unprepared for the

long-term lifestyle changes that occur following their treatment (Newell et al., 2004). Trained nurses used a checklist to provide patients with general information, as well as information on wound care, physical and social problems, work, and finances. However, no differences were found between patients who received this information and those who did not with respect to information needs or satisfaction with information.

Overall, findings are mixed regarding the effectiveness of psychoeducation for patients with HNC. Available studies have small samples which may undermine the accuracy of results and limit their reproducibility. Almost all psychoeducation interventions have been delivered post-treatment and few have been compared with a control group. Furthermore, studies are yet to investigate effects associated with psychoeducation delivered by a trained mental health professional, who may be most proficient at detecting psychological distress and providing individualised help (Peterson et al., 2003). Therefore, additional research is needed before psychoeducation can be recommended as an intervention to improve HNC patient psychological wellbeing.

Cognitive Behavioural Therapy

A total of three RCTs and two non-randomised trials have evaluated the effectiveness of CBT for patients with HNC. In the largest RCT, nurse-led CBT and anti-depressants were compared with standard care among 184 HNC patients who screened positive for smoking, alcohol use, or depression (Duffy et al., 2006). Cognitive behavioural therapy was delivered across 9-11 telephone sessions and medication was prescribed as needed. Those who received the intervention exhibited higher rates of smoking cessation at 6 month follow-up compared to those who received standard care, although no differences in alcohol use or depression were found. The authors noted that despite nurses receiving training in CBT, they were likely more experienced at addressing smoking than problem drinking and depression (Duffy et al., 2006). Furthermore, both newly diagnosed and post-treatment patients were included in the study, making it difficult to determine whether CBT was more beneficial at a particular stage in the disease course.

The two other available RCTs found limited support for CBT. The first of these compared CBT for promoting smoking cessation with general health education in a mixed sample of 109 pre-treatment, active treatment, and post-treatment patients with HNC or lung cancer (Schnoll et al., 2005). At 1 and 3 month follow-ups, no significant differences in 30-day point prevalence abstinence were

found. Patients with HNC were less likely to agree to participate in the study than patients with lung cancer, consistent with other findings that HNC patients frequently decline enrolment in smoking cessation programmes (Schnoll et al., 2004). Only 29% of the sample comprised patients with HNC, making it difficult to determine whether the results are applicable to this group. Kangas and colleagues (2013) utilised a more homogenous sample in their RCT, comparing CBT with non-directive supportive counselling among 35 HNC patients who met criteria for clinical or subclinical cancer-related PTSD, depression, and/or anxiety at time of diagnosis. Both programmes involved six weekly 90 minute sessions across the course of radiotherapy. Although the programmes were found to be equally effective at reducing PTSD, depression, and anxiety from baseline to 1, 6, and 12 month follow-ups, 67% of patients who received CBT no longer met criteria for PTSD, depression, or anxiety by 12 months compared to 25% of patients who received supportive counselling. However, participant dropout from this study was high, primarily due to the physical side effects of radiotherapy.

Studies using non-randomised designs to test CBT have provided promising results but lack methodological rigour. Semple and colleagues (2009) investigated whether targeting CBT to HNC patients experiencing high levels of distress following treatment could improve psychological wellbeing. Fifty-four patients self-selected to receive a CBT intervention or standard care. The intervention involved between two and six 90 minute sessions delivered by a nurse specialist, who visited patients in their homes across a 4-12 week period. The intervention was tailored to each individual patient and addressed a range of HNC specific problems, including eating and drinking, fatigue, appearance, speech, smoking cessation, and financial difficulties. A significant decrease in depression and anxiety and an improvement in social functioning and quality of life were observed among patients one week after the intervention. These results were maintained 3 months later, and were not observed among patients in the standard care group. In another non-randomised trial, HNC patients who had received surgery at some point within the previous four years were assigned to participate in 10 different role play scenarios relevant for people contending with facial disfigurement or to a control group (Fiegenbaum, 1981). Compared to patients in the control group, patients who participated in role play demonstrated significant improvements in self-confidence and social anxiety. Results were maintained at 2 year follow-up, although it was not possible for a comparison between intervention and control group participants (as control participants had since received training).

Collectively, these studies suggest that CBT interventions may benefit some patients with HNC, particularly those reporting high levels of psychological distress. However, only two RCTs have

investigated the impact of CBT on patient psychological wellbeing, both of which have associated limitations. Furthermore, there has been variation across studies regarding the time at which CBT is provided, with the majority investigating CBT post-treatment (or among heterogeneous samples of patients who are pre-, mid-, or post-treatment). The only study that examined CBT in patients undergoing radiotherapy had significant participant dropout. Consequently, it is currently unclear whether CBT provided soon after diagnosis or during treatment can help to reduce the high levels of distress that are typically reported across this time (Haisfield-Wolfe et al., 2009).

Group Interventions

There is limited evidence to support the use of group therapy in patients with HNC, with only two studies conducted to date. Vakharia, Ali, and Wang (2007) compared 24 patients who self-selected to participate in a HNC support group with 23 patients who did not participate. Support group meetings were 90 minutes in duration and occurred biweekly across a 12 month period. The meetings aimed to provide patients with a forum to discuss issues relating to their disease and treatment and were facilitated by a nurse, dietician, speech pathologist, and social worker. Patients who participated in the support group reported better HRQL regarding domains of eating, emotion, and pain, as well as lower global bother and more positive response to treatment. Although these findings appear promising, no baseline assessment of HRQL occurred prior to the support group taking place and participants were not randomised to a condition. Therefore, it is not possible to determine if there were pre-existing differences between the two groups that may explain the results observed.

Another pilot study compared group therapy with a control group in 13 newly diagnosed HNC patients (Hammerlid et al., 1999b). Group therapy meetings were conducted once a week during the first 2 months following diagnosis, fortnightly for the next 2 months, and once a month for 6 months thereafter. The meetings were led by a psychologist who encouraged patients to disclose their thoughts and feelings, and learn from the experiences of others. Only eight participants attended every meeting and although they reported reduced psychiatric morbidity and improved HRQL, this could not be confirmed with significance testing due to insufficient statistical power.

TeleHealth Interventions

Advances in technology have led to a proliferation of interest in techniques that can be used to deliver health information and psychological support electronically, including telemedicine. While

telemedicine initiatives have proven cost-effective and clinically efficacious in a range of illness groups (Bashshur et al., 2009), these benefits cannot be realised if initiatives are not feasible in practice or are unacceptable to the target patient population (Head et al., 2011).

There is evidence that patients with HNC can perceive technical challenges as a barrier to engaging with technology designed to provide information and support. This was demonstrated in a study that assessed whether a comprehensive electronic health information support system delivered to patients discharged from hospital following HNC surgery could enhance HRQL (van den Brink et al., 2007). The support system had previously been found to be well-accepted and appreciated by patients with HNC (van den Brink et al., 2005). The 39 patients who received the intervention showed significantly improved HRQL in 5 of 22 parameters immediately after the intervention relative to a control group. However, only one of these parameters remained significantly different 6 weeks later. In addition, 20 of the 59 patients eligible for the intervention refused to participate in the study, with more than half citing computer-related concerns as their reason for non-participation.

In an effort to circumvent perceived technical challenges associated with computer based systems, a telehealth intervention using a simple telemessaging device has been developed and tested in patients with HNC (Head et al., 2011). The device provided daily education, guidance, and encouragement for patients undergoing initial treatment and was compared with standard care in a RCT. Symptom control algorithms were programmed into the device, which asked patients 3-5 daily questions related to specific symptoms anticipated to occur from the beginning of treatment until 2 weeks post-treatment. Information was provided dependent on patient responses, including recommendations as to when to contact clinicians. While the effects of the intervention are yet to be reported, acceptability and feasibility of the device has been demonstrated. Specifically, participants used the telehealth device across 86% of the total days available for use, and no eligible patients declined to participate because of issues with technology.

Mindfulness

The feasibility of MBSR for HNC patients undergoing radiotherapy treatment has recently been explored. Using a pre-test post-test single group design, Pollard et al. (2016) conducted a pilot study in which 19 patients participated in seven 90-minute mindfulness sessions across the course of radiotherapy. No significant change in mean mindfulness from pre- to post-intervention was observed

for the group as a whole. However, after accounting for participants' baseline mindfulness, higher post-intervention mindfulness was significantly correlated with lower post-intervention psychological distress, including depression and anxiety, higher total quality of life, and better social and emotional wellbeing. While these results are promising, compliance to the intervention (frequency of mindfulness meditation practice) was lower than anticipated and the study participation rate was low. Only 21 of 94 eligible HNC patients consented to take part (22%) and a further two patients dropped out prior to intervention commencement. Therefore, it is unclear whether patients with HNC have the capacity to engage in MBSR while managing the severe side effects associated with radiotherapy.

Review of Interventions

In summary, only a small number of studies have developed and evaluated psychological interventions for patients with HNC in comparison to patients with other types of cancer. There is substantial variation among these studies with respect to types of intervention investigated, modes of delivery, duration, reported outcomes, and methodological rigour. The majority of interventions have employed psychoeducation or CBT techniques (Luckett et al., 2011), and have primarily been delivered by trained nurses or other HNC specialists. Although many interventions have involved individual face-to-face sessions, the number of sessions has differed greatly across studies (ranging from a single session to weekly sessions over a year long period). Several studies have restricted intervention participation to patients experiencing distress, whereas others have offered the intervention to all patients interested in psychological support. Psychological interventions have predominately been delivered in the post-treatment phase, with only one commencing prior to the start of HNC treatment (Katz et al., 2004a). Furthermore, interventions have aimed to improve a diverse range of patient outcomes, including HRQL, depression, anxiety, PTSD, and smoking behaviour, and have used an assortment of measures to do so. The wide divergence across studies investigating interventions among HNC patients prevents inferences regarding which interventions are most effective and in what contexts (Semple et al., 2013).

There are several methodological problems inherent in studies examining psychological interventions for patients with HNC (Howren et al., 2013). Many studies to date have failed to employ a randomised controlled design, instead making use of pre-test post-test (or post-test only) designs with no comparison group or, alternatively, allowing patients to self-select into experimental condition. Lack of random assignment poses a significant threat to the internal validity of study results due to the

potential for pre-existing differences between groups at baseline. A total of four RCTs have published data relating to the effectiveness of psychological interventions at improving outcomes among patients with HNC (Duffy et al., 2006; Humphris & Rogers, 2012; Kangas et al., 2013; Katz et al., 2004a). Each of these studies has been associated with risk of bias due to insufficient information reported regarding methods of random sequence generation, allocation concealment, and blinding of participants, experimenters, and outcome assessors, as well as potential selective reporting of outcomes (Semple et al., 2013). Furthermore, almost all were underpowered to detect effects associated with the intervention under investigation, and none endeavoured to improve patient HRQL. The small sample sizes and dearth of RCTs associated with psychological interventions for patients with HNC are in stark contrast to those associated with other cancers. For example, 34 RCTs were published between 1980 and 2004 examining psychological interventions for breast cancer, 19 of which involved more than 100 patients (Lockett et al., 2011).

There is evidence that patients with HNC are less inclined to participate in intervention studies than other participant groups, although the reasons for this are yet to be fully elucidated (Howren et al., 2013). Participation is low even when interventions are brief and associated with minimal participant burden (Semple et al., 2013), introducing potential for selection bias. Small samples observed in intervention studies for patients with HNC are also related to high rates of participant dropout, which are particularly high among studies that endeavour to provide psychological support across treatment (e.g. Kangas et al., 2013). Reasons for this include the painful physical side effects and extreme fatigue that patients experience during this time, which make it difficult for patients to adhere to multiple sessions while at the same time navigating numerous medical appointments with a diverse range of specialists (Hammerlid et al., 1999b). In addition to limiting statistical power, the small samples associated with studies testing psychological interventions for patients with HNC raise concerns as to whether results would generalise to larger groups of patients.

A Cochrane systematic review has concluded that, due to difficulties with comparability across intervention types, the extensive range of outcomes assessed, and methodological shortcomings (particularly low power), no conclusions can be drawn as to the effectiveness of psychological interventions for patients with HNC (Semple et al., 2013). The authors suggest that in order to improve the quality of future evidence, studies should implement interventions that are theoretically derived using randomised controlled designs and validated outcome measures. Furthermore, power calculations should be conducted prior to recruitment in order to ensure that adequate sample sizes

are attained. It is important that efforts are made to minimise participant dropout, which could be achieved by providing flexibility with respect to the timing and frequency of intervention sessions. Finally, the complete reporting of all relevant details (such as participant selection) is essential to gain an accurate understanding of potential sources of bias.

Psychological Interventions and Caregivers

Despite evidence that caregivers of patients with HNC desire psychological support, interventions to improve adjustment in this group are yet to be developed or tested. Baghi and colleagues (2007) conducted a study in which the closest relatives of patients with HNC were asked about their needs during and after treatment. Seventy-eight of 178 eligible caregivers participated, with the majority (81%) reporting that they would have preferred more detailed information about HNC and available treatment options. A strong need for psychological support was identified, with 60% of caregivers perceiving a need for the patient, and 44% expressing a desire for their own psychological support. Furthermore, 44% of caregivers wished to have contact with self-help groups. Female caregivers were more inclined to consider psychological support necessary than male patients. Similarly, caregivers who were a spouse of the patient (as opposed to another relative) were more likely to want psychological support, as were caregivers who had attained a secondary education. However, 45% of the caregivers sampled reported a belief that their own needs and fears were not relevant in comparison to those of the patient. This suggests that caregivers of patients with HNC may put aside their own needs in order to prioritise those of the patient, potentially contributing to the high rates of psychological distress in this group (Longacre et al., 2012).

Given that a substantial proportion of caregivers perceive that psychological support would be beneficial (Nightingale et al., 2016b), and evidence that these individuals may be more vulnerable to psychological distress than patients themselves (Verdonck-de Leeuw et al., 2007), interventions designed to provide information and support to HNC patients could be extended to incorporate their caregivers. Individuals rarely cope with chronic illness in isolation of others, as is recognised in the social support literature (Schwarzer & Knoll, 2007). The coping behaviours of others, particularly spouses, can influence the adoption of patients' coping behaviours and subsequent wellbeing (Badr, Yeung, Lewis, Milbury, & Redd, 2015). This idea has been developed and investigated using models of 'dyadic coping', whereby two or more people are proposed to simultaneously appraise the threat associated with a stressor and take joint responsibility for managing the stressor (Lyons, Mickelson,

Sullivan, & Coyne, 1998). For example, Berg and Upchurch (2007) established a developmental-contextual model which specifies that the coping strategies adopted by a patient to manage chronic illness will be in relation to those adopted by their spouse, and vice versa. The model suggests that use of collaborative coping strategies is most beneficial for the dyad. However, the capacity to use these dyadic or collaborative coping strategies will be influenced by: sociocultural factors, such as culture and gender, as well as context specific factors, including relationship quality and the specific demands of an illness (Berg & Upchurch, 2007).

Qualities of a relationship that can facilitate dyadic coping in response to cancer have been identified, including relationship awareness (a perception of stress as 'our stress'), authenticity (an ability to honestly disclose feelings), and mutuality (the capacity to empathise) (Kayser, Watson, & Andrade, 2007). It is plausible that interventions involving both HNC patients and their caregivers would encourage the development of these qualities, thereby fostering effective dyadic coping, and improving patient and caregiver psychological health. Indeed, semi-structured interviews involving 13 patients with incurable HNC and their caregivers found that effective dyadic coping occurred when dyads discussed important issues, cared for one another, and faced challenges together as a unit (Foxwell & Scott, 2011). This finding has been replicated more recently in a study involving 123 HNC patient-caregiver dyads who engaged in a videotaped discussion about cancer in the laboratory (Badr et al., 2016). Patients and caregivers who frequently used 'we-talk' (as opposed to 'I-talk' or 'you-talk') reported more positive mood following the discussion, as well as lower levels of distress 4 months later.

Although few interventions specifically designed for caregivers of patients with cancer have been investigated, available research suggests that they are feasible to deliver (Harding & Higginson, 2003), and have potential to improve caregiver adjustment. McMillan et al. (2006) conducted a RCT in which 354 family caregivers of hospice patients with advanced cancer were assigned to receive standard hospice care, standard care in addition to three supportive visits, or standard care in addition to a coping skills intervention. Supportive visits were delivered by a trained nurse and involved discussions of feelings, fears, and the patient-caregiver relationship. In contrast, the coping intervention (consisting of three sessions of the same duration as the supportive visits and delivered by the same nurse), taught caregivers problem solving skills designed to improve management of medical and psychosocial problems. While considerable attrition occurred among each group, the coping skills intervention improved caregiver quality of life and reduced burden regarding patient symptoms and

tasks related to caregiving at 2 week follow-up, in comparison to both standard care and supportive visits. Research is needed to determine if similar interventions may be applied with the same success in caregivers of patients with HNC.

While interventions are yet to be developed with the sole purpose of improving HNC caregiver adjustment, one investigation has examined the efficacy of a day-long multiple family group programme for both patients with HNC and their caregivers (Ostroff et al., 2004). Eighty eligible families were invited to attend the programme, which aimed to facilitate the discussion of cancer experiences among and between families approximately 6-12 months after patient treatment (Steinglass, Ostroff, & Steinglass, 2011). Despite extensive efforts to maximise participation (including condensing the programme from 6 weeks to 6 hours in duration), only 15 of 80 (19%) families agreed to take part in the programme. Approximately half of those who did not participate cited that they were not interested, while the other half reported logistical reasons for their non-participation (e.g. location, illness, scheduling conflict). It is important to note that families who attended the programme were highly satisfied, with almost all stating that they would recommend the programme to other families managing HNC.

There is a clear need for psychological support to be extended to include HNC caregivers, particularly in light of evidence that these individuals would appreciate assistance to manage their distress (Baghi et al., 2007; Nightingale et al., 2016b). Such psychological support must be provided in a way that increases the feasibility of participation but is also appealing to caregivers, perhaps by targeting concerns and challenges that are unique to their role.

Self-Regulatory Interventions

Previous research presented in Chapter 2, as well as the associations examined in Study One of this thesis, highlight that illness perceptions and coping at diagnosis are related to future psychological outcomes in both patients with HNC and their caregivers. These findings, and the specifications of the CSM (Leventhal et al., 1980), suggest that cognitively based interventions designed to modify inaccurate and pessimistic perceptions of HNC may encourage the use of adaptive coping strategies, leading to improvements in psychological wellbeing. The amenability of illness perceptions to change provides greater potential for intervention than other immutable factors related to psychological wellbeing in the context of HNC (such as cancer and treatment-related characteristics, sociodemographic variables, and personality). Furthermore, use of the CSM as a guiding theory

facilitates the development of interventions designed to change illness perceptions, and assists with interpretation of intervention effects.

Interventions designed to change patient illness perceptions and coping in an effort to facilitate patient recovery are known as self-regulatory interventions (Petrie, Broadbent, & Meechan, 2003). Such interventions are typically brief (conducted across several 30-60 minute sessions) and delivered by a registered health psychologist. The aim of each session is to adjust beliefs that are most pertinent to the particular illness of the patient in a way that produces positive changes in behaviour and subsequent health outcomes. At the beginning of a self-regulatory intervention an assessment of illness perceptions is typically undertaken using one of the many validated questionnaires developed for this purpose (e.g. Broadbent et al., 2006; Moss-Morris et al., 2002; Weinman, Petrie, Moss-Morris, & Horne, 1996). This enables intervention content to be individually tailored to each patient, identifying which perceptions should be modified in order to foster the most adaptive and accurate model of illness. Perceptions can be modified by providing patients with specific information about their illness and treatment, and by using established cognitive behavioural techniques such as cognitive restructuring and behavioural assignments (Broadbent & Richardson, 2014). Self-regulatory interventions also typically include the provision of an individualised action plan (Leventhal et al., 1984). The action plan is developed in collaboration with the patient and documents what, where, when, how, and with whom coping strategies can be used to manage the illness, treatment, and any associated distress.

Efficacy of Self-Regulatory Interventions

Interventions that target patient illness perceptions have diverse applicability, including potential for use across a broad range of illness groups, in varied contexts and at distinct time points, via multiple modes of delivery (Petrie & Weinman, 2012). While only one study has examined the efficacy of a self-regulatory intervention for patients with cancer (Humphris & Rogers, 2012), these interventions have proven successful at modifying beliefs and improving physical and psychological health in patients with other conditions. Illness perception interventions have been particularly successful at promoting recovery from myocardial infarction (MI). Petrie et al. (2002) conducted a RCT in which 65 MI patients were assigned to receive three sessions designed to modify illness perceptions in addition to standard care, or to standard care alone. Patients who received the intervention perceived less serious consequences, a shorter timeline, increased treatment control, and lower

symptom distress immediately after the intervention in comparison to patients who received standard care. Differences in perceptions of timeline and treatment control were maintained at 3 month follow-up. Patients who received the intervention also reported feeling better prepared to leave hospital, experienced fewer angina symptoms, and returned to work more quickly than those who did not. These findings were replicated in a second RCT, where the intervention was adapted to include an additional session involving both patients and their spouses (Broadbent, Ellis, Thomas, Gamble, & Petrie, 2009b). Not only did intervention patients return to work at a faster rate than patients who received standard care, but their spouses reported positive changes in perceptions of MI, as well as less worry, reduced anxiety about patient exercise and medications, and lower distress regarding patient symptoms (Broadbent et al., 2009a).

Other illness populations in which self-regulatory interventions have produced positive changes in illness perceptions include diabetes and psoriasis. Specifically, targeting illness perceptions in patients with poorly controlled type 2 diabetes and their family members increased patient perceptions of control and understanding, improved adherence to diet and exercise recommendations, and enhanced glycaemic control (Keogh et al., 2011). For patients with psoriasis, targeting CBT to implicit illness models resulted in significant reductions in perceived symptom frequency and severity, as well as reductions in perceived consequences and emotional attributions (Fortune, Richards, Griffiths, & Main, 2004). Furthermore, a RCT comparing a brief in-home illness perception intervention with standard care (accounting for researcher attention) found that the intervention had increased daily walking 4 months later among individuals experiencing intermittent claudication (Cunningham, Swanson, O'Carroll, & Holdsworth, 2012). This finding was maintained 1 and 2 years post-intervention (Cunningham, Swanson, Holdsworth, & O'Carroll, 2013).

Technology is increasingly employed in interventions designed to modify patient illness perceptions. Adherence to preventer medication was improved in 216 young adults with asthma by sending text messages individually tailored to their illness and treatment beliefs across an 18-week period (Petrie, Perry, Broadbent, & Weinman, 2012). Interventions that aim to modify perceptions by using new technologies to provide visual demonstrations of illness are also proving successful. Jones and colleagues (2015) found that a brief animated intervention aiming to foster accurate perceptions of acute coronary syndromes improved patient perceptions of treatment control and decreased concerns about medications immediately after the intervention. Additionally, the intervention increased patient timeline beliefs, decreased symptoms, lowered cardiac avoidance, increased exercise, and facilitated

return to normal activities 7 weeks later. Visual demonstrations have also been used to increase the goodness of fit between patient models of illness and treatment resulting in improved adherence to medication among patients with end-stage renal disease (Karamanidou, Weinman, & Horne, 2008).

The above studies suggest that brief, straightforward psychological interventions can be employed to identify and change negative illness perceptions, which in turn promote improvements in a diverse range of health outcomes, among varied patient populations (Petrie & Weinman, 2012). However, the benefits associated with targeting illness perceptions have received limited attention in the context of cancer. While a study has examined an intervention based on the CSM for women undergoing breast cancer treatment, this intervention focused on targeting emotion regulation processes specified in the model and occurred in the context of a 12-week group psychosocial support programme (Cameron, Booth, Schlatter, Ziginas, & Harman, 2007). Results found that the programme improved patient use of relaxation-oriented techniques, enhanced perceived control, emotional wellbeing, and coping efficacy, and reduced risk of recurrence, cancer worry, and anxiety. Reductions in emotional suppression across the first year following diagnosis were also observed among intervention participants. While these results demonstrate benefits of targeting emotional representations of breast cancer, it remains unclear whether cognitive perceptions can be modified to improve outcomes for this group, with calls for further research in this area (Kaptein et al., 2015).

Self-Regulatory Interventions and Head and Neck Cancer

To date, only one study has investigated an intervention that addressed illness perceptions among patients with HNC. In a RCT involving 87 patients, the adjustment to the fear, threat, or expectation of recurrence (AFTER) intervention was delivered and compared with standard care approximately 7-11 months post-treatment (Humphris & Rogers, 2012). Based on Leventhal's CSM, the nurse-led AFTER intervention occurred across a maximum of six sessions and aimed to address recurrence fears through an exploration of patient illness beliefs and behaviours (Humphris & Ozakinci, 2008). In comparison to those who received standard care, patients who participated in the intervention had lower levels of recurrence fears and anxious preoccupation immediately after the completion of sessions. However, these results were no longer observed 15 months post-treatment, and no difference in general anxiety or depression was found in response to the intervention.



More research is needed to investigate whether self-regulatory interventions can improve psychological adjustment to HNC, given that limited conclusions can be drawn from the single study in this patient group (Humphris & Rogers, 2012). While this RCT is the only intervention study in patients with HNC to include a power calculation, the target of 53 patients per group was not reached, and there was significant dropout throughout the study. Furthermore, few patients attended all six sessions of the intervention, with the majority attending a single session only. The intervention was delivered several months post-treatment and aimed to target fear of recurrence. However, the strongest (and most frequently documented) relationships between illness perceptions and outcomes among patients with HNC relate to HRQL (Scharloo et al., 2010; Llewellyn et al., 2007a) and psychological distress (Dempster et al., 2011b; Llewellyn et al., 2007b). These relationships have been documented as early as diagnosis, a time at which patients wish to receive psychological support, suggesting that self-regulatory interventions delivered at this time point may afford the greatest benefit. Targeting perceptions at diagnosis would enable maladaptive perceptions to be modified prior to treatment commencement, potentially improving the way in which patients manage this difficult time and their subsequent recovery as a result. Finally, self-regulatory interventions that include caregivers of patients with HNC are required to determine whether such interventions can be helpful for this group, as has been documented in other illnesses.

Summary

Few studies have examined psychological interventions for patients with HNC, particularly in comparison to patients with other types of cancer (Lockett et al., 2011). Across the studies that have investigated psychological interventions for HNC patients there is considerable variability with respect to intervention types, timing and delivery, and outcome measures used. In addition, the majority of studies have not employed a randomised controlled design, are underpowered to detect significant effects, and have not involved long-term follow-up. Therefore, it is not possible to determine whether any of the psychological interventions conducted to date can reliably improve outcomes for patients with HNC, and whether improvements can be sustained over time.

Further development and investigation of psychological interventions that can improve post-treatment HRQL and psychological wellbeing among patients with HNC is needed. Although most studies have been delivered in the post-treatment phase, there is evidence that patients would appreciate support earlier in order to manage the distress associated with their diagnosis and

treatment (Hammerlid et al., 1999b). Providing interventions early after diagnosis may help to prevent the development of enduring psychological problems. However, difficulties with recruitment and participant dropout are common problems encountered when intervening with HNC patients, particularly when interventions are provided during treatment. Consequently, it is essential that interventions delivered across this time are brief and flexible, whereby the timing of sessions is coordinated with patient medical appointments, as well as patient physical symptoms and fatigue. Such interventions could be adapted to include caregivers of patients with HNC. Not only do this group report high levels of distress and burden, but also a desire for psychological support.

Self-regulatory interventions designed to target illness perceptions and coping have potential to improve psychological outcomes in both patients with HNC and their caregivers. These interventions are theoretically derived and target variables that have been cross-sectionally and longitudinally related to HNC patient and caregiver psychological outcomes. Furthermore, self-regulatory interventions are typically brief (requiring minimal patient time and energy) yet effective. Evidence to support this is provided by numerous studies in a diverse range of illness groups, where modifying illness perceptions and coping has been found to improve psychological wellbeing and hasten recovery. The advantages associated with self-regulatory interventions and their applicability to HNC suggests that further research, in the form of a RCT, could help to determine the efficacy of this approach for improving patient and caregiver adaptation to the disease.

Chapter 9. A Self-Regulatory Intervention for Patients with Head and Neck Cancer

Preface

In the previous chapters of this thesis, the contribution of illness perceptions and coping to the psychological wellbeing of patients with HNC and their caregivers has been highlighted. Interactions between patient and caregiver illness perceptions were also identified, as well as relationships between these interactions and patient HRQL across the disease trajectory. The results suggest that psychological interventions based on the CSM may be effective at improving HRQL and reducing the high rates of psychological distress that are frequently reported among individuals affected by HNC. However, only one study to date has investigated an intervention designed to modify illness perceptions and coping among patients with HNC, and this was delivered in the post-treatment phase (Humphris & Rogers, 2012). Further research is needed to establish whether providing these interventions earlier in the disease trajectory can improve the way in which patients manage treatment, and their subsequent adjustment to HNC. It is also important to determine whether psychological interventions may be adapted to incorporate both patients and their caregivers (Howren et al., 2013).

Few studies have examined psychological interventions for patients with HNC in comparison to patients with other types of cancer (Luckett et al., 2011). Furthermore, available studies have a number of methodological shortcomings which preclude conclusions regarding the utility of these interventions (see Chapter 8). In order to address these limitations, including low rates of participation and high dropout, an intervention was developed that aimed to take into account patient and caregiver preferences for psychological support. Qualitative results obtained from Study 1 suggested that these individuals desired a brief intervention, delivered soon after diagnosis, providing information about the symptoms and treatment associated with HNC, and coping strategies that could be used to manage distress. These requests align with the format of self-regulatory interventions, which are typically delivered across only three sessions, and use individually tailored information to address maladaptive illness perceptions and promote the use of adaptive coping (Petrie et al., 2003).

The following manuscript documents the results from Study 2 of this thesis; a pilot RCT testing a self-regulatory intervention for patients with HNC. The use of a pilot randomised controlled design as

well as a theory-based intervention are significant strengths of the study, and have been notably absent from the majority of studies investigating psychological interventions for this patient group (Semple et al., 2013). Patients were encouraged to invite a caregiver to participate in the study in light of the important role these individuals play in patient adjustment to HNC, the difficulties related to their own psychological adjustment, and their frequently expressed desire for psychological assistance (Baghi et al., 2007; Hanly et al., 2016; Nightingale et al., 2016b).

Citation

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Abstract

Background: Research is yet to investigate whether psychological interventions delivered early after diagnosis can benefit patients with HNC. The aim of this study was to investigate the effectiveness of a brief self-regulatory intervention (targeting illness perceptions and coping) at improving HNC patient HRQL.

Methods: A pilot RCT was conducted, in which 64 patients were assigned to receive three sessions with a health psychologist in addition to standard care or standard care alone. Participants completed questionnaires assessing HRQL, general distress, and illness perceptions at baseline and again 3 and 6 months later.

Results: Compared to the control group, patients who received the intervention had increased treatment control perceptions at 3 months ($p = .01$), and increased social quality of life at 6 months ($p = .01$). The intervention was particularly helpful for patients exhibiting distress at baseline.

Conclusion: A brief psychological intervention following HNC diagnosis can improve patient perceptions of treatment and social quality of life over time. Such interventions could be targeted to patients who are distressed in order to confer the greatest benefit.

Background

Patients with HNC must contend not only with a significant threat to mortality, but also highly distressing symptoms and treatment. Changes in the ability to breathe, speak, swallow, and eat are commonly associated with the disease (Howren et al., 2013), as well as pain and disfigurement that is difficult to conceal (List & Bilir, 2004). These factors have an enduring effect on patient HRQL (Mehanna & Morton, 2006), and have led to the suggestion that HNC is the most emotionally traumatic cancer to experience (Bjorklund et al., 2010). Patients report particularly low HRQL during and immediately after treatment as they manage severe side effects that impact all aspects of wellbeing (Hammerlid et al., 2001).

The implications of HNC for patient HRQL, and the variation in this outcome among individual patients (Howren et al., 2013), suggests that interventions to optimise HRQL following treatment are needed. While psychological interventions have proven effective at improving HRQL in patients with other cancer types (Rehse & Pukrop, 2003), there is limited evidence for their utility in patients with HNC. The most common forms of intervention evaluated for this group are psychoeducation and CBT (Lockett et al., 2011), although few RCTs have been conducted (Duffy et al., 2006; Kangas et al., 2013; Katz et al., 2004a) and rates of participant dropout are high. A recent Cochrane review concluded that shortcomings in the design and reporting of studies testing psychological interventions for HNC patients prevent any conclusions regarding their effectiveness (Semple et al., 2013).

Psychological interventions based on Leventhal's (1980) CSM may be beneficial for patients with HNC. The CSM proposes that when individuals are faced with a health threat they form parallel cognitive and emotional representations. Both sets of representations interact to generate unique coping behaviours to manage the health threat and its associated emotions. Continuous appraisal of the outcomes of these behaviours is proposed to occur which can lead to the modification of initial representations (Wearden & Peters, 2008). Cognitive representations include perceptions of the consequences, duration (timeline), symptoms or label (identity), causes, and controllability of an illness (Leventhal et al., 1984). Emotional representations describe the emotional impact of an illness. Recent measures have also included assessments of overall illness understanding or coherence (Broadbent et al., 2006; Moss-Morris et al., 2002).

Evidence to support the CSM has been found across a diverse range of patient groups (Hagger & Orbell, 2003), including patients with HNC (Richardson et al., 2015a). For example,

perceiving a long timeline and many consequences of the disease at diagnosis has predicted lower HRQL 2 years later (Scharloo et al., 2010). Similarly, long timeline perceptions have predicted HNC patient depression 6-8 months post-treatment (Llewellyn et al., 2007b). Dempster et al. (2011b) also showed that changes in perceptions of oesophageal cancer over time were associated with changes in patient depression and anxiety, particularly perceptions of personal and treatment control. There is preliminary research to suggest that illness perceptions may also contribute to psychological wellbeing among individuals caring for patients with HNC. These caregivers experience high levels of distress (Longacre et al., 2012), particularly anxiety (Hodges & Humphris, 2009) and PTSD symptoms (Posluszny et al., 2014). One study found that illness perceptions and coping strategies explained between 35% and 49% of the variance in depression and anxiety reported by caregivers of patients with oesophageal cancer (Dempster et al., 2011c). More recently, caregiver perceptions of low treatment control and a strong illness identity at HNC diagnosis predicted greater PTSD symptomology 6 months later (Richardson et al., 2016c). Collectively, these findings suggest that illness perceptions could be targeted in psychological interventions that aim to improve psychological outcomes among HNC patients and their caregivers.

Self-regulatory interventions aim to change illness perceptions and coping through the provision of individualised information and coping techniques. Self-regulatory interventions have proven effective at improving a broad range of outcomes in other patient populations, including MI patients and their spouses (Petrie et al., 2002; Broadbent et al., 2009a), as well as patients with acute coronary syndromes, coronary heart disease, renal disease, and diabetes (Cossette, Frasure-Smith, Dupuis, Juneau, & Guertin, 2012; Goulding, Furze, & Birks, 2010; Karamanidou et al., 2008; Keogh et al., 2011). Research suggests that such interventions may be successfully applied in both patients and caregivers (Broadbent et al., 2009b).

Only one study to date has tested a self-regulatory intervention for patients with HNC. In this RCT, 90 outpatients previously treated for oral and oral pharyngeal cancer were assigned to receive either six weekly sessions delivered by a trained nurse specialist (the AFTER intervention), or usual care (Humphris & Rogers, 2012). The aim of the intervention was to explore illness beliefs and behaviours and develop relaxation skills in order to reduce fear of cancer recurrence and anxiety. Although patients who received the intervention exhibited less fear of recurrence and anxious preoccupation, these results were not sustained over time. A potential explanation is that compliance to the intervention was low, with only 14 of 53 patients attending all six sessions. The AFTER

intervention was delivered between 7-11 months post-treatment, although there is evidence that HNC patients would appreciate psychological support at time of diagnosis and during treatment (Richardson et al., 2015b). Given that marked deterioration in HRQL is typically observed across this time, early interventions may be of greater benefit than those delivered later in the disease trajectory. Participant dropout and difficulties with adherence to the AFTER intervention, and other psychological interventions for patients with HNC (Ostroff et al., 2004), also suggest that brief and flexibly timed interventions may be most appropriate. Finally, studies are yet to investigate whether self-regulatory interventions can improve HNC patient HRQL, an outcome for which there is considerable unexplained variation (Howren et al., 2013).

Efforts to improve HRQL among patients with HNC are particularly important because of the long-term impact of the disease on physical, social, and psychological wellbeing, and the well-established associations between HNC patient HRQL and clinical outcomes, including disease-specific and overall survival (van Nieuwenhuizen, Buffart, Brug, Leemans, & Verdonck-de Leeuw, 2015). The primary aim of this study was to determine whether a brief self-regulatory intervention based on the CSM could improve HRQL in patients with HNC. We hypothesised that patients randomly assigned to receive the intervention would demonstrate positive changes in illness perceptions, HRQL, and levels of distress, approximately 3 and 6 months after diagnosis in comparison to patients assigned to standard care. A secondary aim of the study was to assess whether the intervention could also produce positive changes in caregiver illness perceptions and distress levels.

Methods

Design

A pilot RCT was tested utilising a parallel design. Patients were randomly allocated to receive the self-regulation intervention or to standard care based on a 1:1 allocation ratio. Randomisation was performed by a researcher independent of the study using a randomisation table generated by computer software. The randomisation sequence was concealed in sealed envelopes until patients consented to participate, at which point group allocation was assigned. While the researchers and psychologist responsible for delivering the intervention were not blind to group allocation, all care providers were blind to condition assignment.

Participants

Participants were a consecutive sample of patients diagnosed with a primary epithelial head and neck cancer (carcinoma in the pharynx, larynx, oral cavity, sinonasal cavity), or metastatic skin cancer in the head and neck region, and their caregivers, attending a multidisciplinary head and neck clinic meeting at Auckland City Hospital between August 2014 and July 2015. Patients were required to have received a diagnosis within 3 weeks prior to their clinic attendance, as well as a treatment plan of one or more treatments (surgery, radiotherapy, chemotherapy). Only adult patients were included in the study, with those aged between 18 and 90 years of age eligible to participate. Exclusion criteria were conditions that would interfere with participation (including severe substance dependence, active psychosis, cognitive impairment, or significant physical disability). Non-English speaking patients were also excluded, as well as those to be treated with palliative intent. Eligible caregivers included those identified by the patient as a spouse, family member, or close friend.

Power Calculation

The AFTER intervention trial found an effect size of $d = 0.7$ for reducing anxious preoccupation in patients with HNC (Humphris & Rogers, 2012). Setting power at 0.80, and alpha at .05, G-power software (Faul et al., 2007) indicated that a sample of 68 patients would be needed to detect a similar effect. However, we aimed to recruit a total sample of 100 patients to account for participant attrition.

Procedure

The study was registered with the Australian New Zealand Clinical Trials Registry and ethical approval was obtained from the Health and Disability Ethics Committee and the Auckland District Health Board Research Review Committee. Patients were screened for eligibility by both an HNC nurse specialist and an otorhinolaryngologist. Eligible patients were approached after meeting the multidisciplinary team and provided with an information sheet about the study. Patients were asked for their permission to be contacted in the next week regarding participation. Those who gave permission were contacted by phone at this time point by the first author and verbally consenting individuals were posted a written consent form and baseline questionnaire. They were then randomly allocated to the intervention or standard care condition. Patients in the intervention group were contacted within the next week to organise their session times with the registered health psychologist responsible for

delivering the intervention. They were encouraged to invite a spouse, partner, or close friend to attend the intervention sessions.

All participants were asked to complete questionnaires at baseline and again 3 and 6 months post-diagnosis. These were sent by mail with a return freepost envelope and assessed demographics, HRQL, distress, and illness perceptions. Postage questionnaires allowed patients to complete questionnaires in the absence of the researchers, who may have inadvertently influenced responding. Participants were contacted by the researchers in order to ensure that questionnaires were completed within 2 weeks of each assessment point. Medical information was obtained from patient medical records.

Standard Care

Patients diagnosed with HNC are required to attend a multidisciplinary clinic meeting at which a diverse range of specialists confer to identify the most appropriate treatment plan. Once this plan has been determined, consultants are available to discuss details of diagnosis and treatment with patients. Patients to be treated with surgery are provided information sheets specific to their surgical procedure that detail what the surgery will involve, approximate length of hospital stay, and whether a tracheostomy is needed. These patients also attend a pre-operation anaesthetic review with a nurse, who provides further information relating to the planned procedure. Patients to be treated with radiotherapy are presented with an information booklet on the day of their multidisciplinary clinic meeting which describes the duration and side effects of this treatment. They are also invited to attend a welcome meeting at the radiotherapy department where they can receive general information from radiation oncologists and become familiar with the department and staff. If chemotherapy is required this is mentioned at the initial multidisciplinary meeting but is discussed in more detail at a subsequent chemotherapy orientation run by nurses. All patients receive a clinic letter documenting and explaining the decision to treat. Referrals to the Cancer Society (a non-government organisation that endeavours to reduce the impact of cancer on individuals and the community) are made with patient permission. Patients also have the contact details of HNC nurse specialists who may be contacted regarding any concerns that arise from time of diagnosis through to the completion of treatment.



Intervention

The intervention consisted of three 60 minute face-to-face sessions with a health psychologist. The timing of these sessions was flexible and organised around patient medical appointments and treatment. The first session was arranged to take place prior to treatment commencement, the second towards the beginning of treatment, and the third session towards the end of treatment. A 30 minute follow-up phone call also took place approximately 3 weeks after the final session. Intervention sessions took place at hospital or at patients' homes, depending on their personal preference.

The content of each intervention session was based on the CSM (Leventhal et al., 1980). Intervention participants completed a brief assessment of illness perceptions at the beginning of each session. Based on these assessments, individually tailored information about HNC was provided. Specifically, perceptions of consequences were addressed with information regarding the specific side effects associated with treatment (which may have been surgery, chemotherapy, radiotherapy, or a combination); perceptions of timeline were targeted with information regarding the likely duration of treatment and recovery and the associations these have with cancer stage; perceptions of personal control, concern, and emotional impact were addressed by describing and providing coping strategies to manage side effects of treatment, as well as strategies for the management of distress; treatment control perceptions were managed through the provision of information regarding how different treatment approaches are used to cure the disease; perceptions of illness identity were targeted with information regarding the specific symptoms associated with patient diagnosis; and coherence and causal perceptions were addressed with comprehensive information about HNC, including the types, causes, methods of diagnosis, stages, treatment, and likely side effects. This differed to the information provided to patients receiving standard care alone, which was not tailored to address existing perceptions.

The focus of the first intervention session was improving patient understanding of HNC and its treatment in order to encourage accurate and informed illness perceptions. This was largely achieved through the provision of information about the disease. The second session focused on the development of coping strategies that could be used to manage distress, symptoms of the disease, and treatment side effects. The psychologist and patient worked together to develop an action plan specifying when, where, how, and with whom coping strategies might be implemented. Coping strategies were targeted to an issue identified by the patient as problematic. For example, patients who

identified stress as an issue were provided with relaxation techniques, patients experiencing distress were supported with cognitive restructuring, positive activity scheduling, and self-care techniques, and patients with challenging symptoms were provided with options for their management (e.g. techniques for the alleviation of a dry or sore mouth, difficulty swallowing, trouble speaking, and pain). Coping strategies were not discussed or developed among patients who received standard care. The final intervention session evaluated the effectiveness of coping strategies and prepared patients for what to expect following the completion of treatment. This session also addressed concerns about the future (including fear of cancer recurrence) and aimed to normalise these. In contrast, standard care did not include any discussion regarding common experiences post-treatment and how these might be addressed.

An educational manual of materials entitled 'Head and Neck Cancer: A Guide for Patients and their Family Members' was developed as part of this study and provided to patients as a supplement to intervention sessions. This manual was divided into sections that included information on: head and neck cancer (types, causes, symptoms, and stages); treatment (surgery, chemotherapy, and radiotherapy); side effects; coping; managing relationships (with family members, children, friends, and health care professionals); and support available in the community. The information provided was more comprehensive than the material provided to patients receiving standard care. Standard care information addressed physical and practical considerations relevant to HNC, whereas the intervention manual also considered psychosocial aspects of the disease, providing specific suggestions regarding how these may be managed. Furthermore, the manual format allowed patients to access all information from a single source. This contrasts with standard care information which was distributed across several individual resources.

The health psychologist conducting sessions was required to engage in several practice sessions with individuals acting as patients prior to recruitment. Each practice session revolved around a unique HNC case (which was varied in relation to patient age, gender, cancer stage, and treatment type). Fidelity to intervention content was assessed by the first and second author who rated the extent to which the health psychologist successfully addressed issues relevant to each session. This included identifying and modifying inaccurate illness perceptions in session one, discussing coping and providing strategies for the management of distress and treatment side effects in session two, and assisting with patient concerns for the future in session three. Regular meetings were held over the course of the study between the researchers and the psychologist delivering the intervention.

Measures

The primary outcome was patient HRQL. Secondary outcomes were distress and illness perceptions.

Functional Assessment of Cancer Therapy – Head and Neck (FACT-H&N)

The FACT-H&N is a multidimensional questionnaire specifically designed to measure HRQL in patients with HNC (Cella et al., 1993). There are four core subscales comprised of 27 items that index physical, social, emotional, and functional wellbeing. A supplementary scale consists of 12 items designed to assess head and neck specific wellbeing. The physical wellbeing subscale collects information related to patient experiences of symptoms (including fatigue, nausea, and treatment side effects) and whether these are limiting engagement in daily activities. The social subscale requires patients to rate their satisfaction with the support they receive from their family members and friends, as well as satisfaction with family communication about HNC, and feelings of closeness to others. The emotional subscale assesses patient feelings (such as sadness, worry, and hopelessness), the functional subscale assesses patient capacity to function across diverse settings (including work and home), and the head and neck specific subscale assesses the degree to which patients are impacted by the unique challenges of the disease, including eating, swallowing, breathing, and speech difficulties. Ratings on items for each domain are summed to form a total HRQL score, with higher scores indicative of better HRQL. The questionnaire has demonstrated validity, reliability, and sensitivity in HNC patient samples (Cella et al., 1993; List et al., 1996). Internal consistency was excellent in the present study, with $\alpha = .89$ for total HRQL at baseline, $\alpha = .94$ for total HRQL at 3 months, and $\alpha = .93$ for total HRQL at 6 months.

General Health Questionnaire-12 (GHQ-12)

The GHQ-12 is a brief, reliable, and sensitive measure for assessing symptoms of psychological distress (Goldberg, 1992). Respondents are asked to rate the degree to which they agree with each item on a 4-point scale. The 12 items are summed to form a total score. Higher scores reflect higher distress, with scores greater than 15 indicating distress that is clinically significant. Reliability coefficients have been found to range from .78 –.95 in a number of studies (Jackson, 2007) and the validity of the questionnaire is well-established (Goldberg, 1992). Alphas in the present study were .83, .90, and .90 at baseline, 3 months, and 6 months, respectively.

Brief Illness Perception Questionnaire (Brief-IPQ)

The Brief-IPQ is a nine-item scale designed to efficiently measure individual perceptions of illness (Broadbent et al., 2006). Each perception is assessed with one item rated on a 0-10 scale. Five items assess cognitive representations (consequences, timeline, personal control, treatment control, and identity), two items assess emotional representations (concern and emotional impact), and one item assesses illness comprehensibility (coherence). The scale also includes an open-ended item where respondents are asked to rank the three most important causes of their illness (Broadbent et al., 2006). The Brief-IPQ is widely used and has good psychometric properties (Broadbent et al., 2015).

Satisfaction with Intervention

Participants in the intervention group were asked to answer four open-ended questions. These questions aimed to assess general satisfaction with sessions received, aspects of the intervention that were considered most beneficial, aspects of the intervention that could be improved upon, and whether the intervention could be recommended to other patients diagnosed with HNC.

Analysis

Analyses were performed using SPSS version 22 software. ANCOVA was used to investigate differences in change scores between groups (for both primary and secondary outcomes) at 3 and 6 month follow-ups, while controlling for baseline scores. Comparisons were made between patients assigned to the intervention and patients assigned to the control group (intention to treat analyses), as well as between patients who received the entire intervention and those who did not (per protocol analyses). Analyses were performed when including cancer stage and radiotherapy treatment as covariates because of their potential relationship with patient HRQL. Subgroup analyses were also performed to investigate the effects of baseline distress on intervention effectiveness; only patients scoring >10 on the GHQ-12 were included. Although scores >15 are considered the cut-off for clinical distress, only 11 patients met this criteria at diagnosis. In contrast, 33 patients scored >10. This cut-off was close to the mean score on the measure at baseline ($M = 11.98$, $SD = 4.38$), which has been proposed as a rough guide to the optimum threshold (Goldberg, Oldehinkel, & Ormel, 1998). For all tests, a 2-sided p -value less than .05 was considered statistically significant. Missing data was addressed using the method of pairwise deletion.

Results

One hundred and seventy patients were screened for eligibility (Figure 4). Of these patients, 139 met eligibility criteria and 64 consented to take part, resulting in a 46% participation rate. No significant differences were found between eligible patients who declined participation and those who consented with respect to gender ($p = .60$), cancer stage ($p = .61$), and radiotherapy status ($p = .32$). However, a greater proportion of consenting patients received more than one treatment (44/62) compared to non-consenting patients (37/74), $X^2(1, 136) = 6.16, p = .01$, and a greater proportion of patients who declined to participate died in the 12 months following their diagnosis (14/75) compared to those who consented (1/64), $X^2(1, 139) = 10.49, p < .01$.

Following randomisation, two patients were excluded due to further tests revealing non-cancerous tumours (subsequent to their multidisciplinary clinic visit and provision of consent). Of the 31 patients assigned to the intervention group, 27 completed all intervention sessions, representative of a 13% attrition rate. Two patients attended one intervention session only and two patients did not attend any sessions. Patient demographic and medical characteristics are presented in Table 21.

Seven patients in the intervention group had a caregiver participate compared to 11 patients in the control group. Six of the caregivers in the intervention group were spouses of the patient (86%) and one was a family member (14%). In the control group, six caregivers were spouses (55%), three were family members (27%), and two were friends (18%). Six of the seven caregivers in the intervention group participated in every intervention session with the patient, while one caregiver in this group participated in no intervention sessions. Results regarding caregiver outcomes are not presented due to insufficient statistical power.

Figure 4. CONSORT flow chart

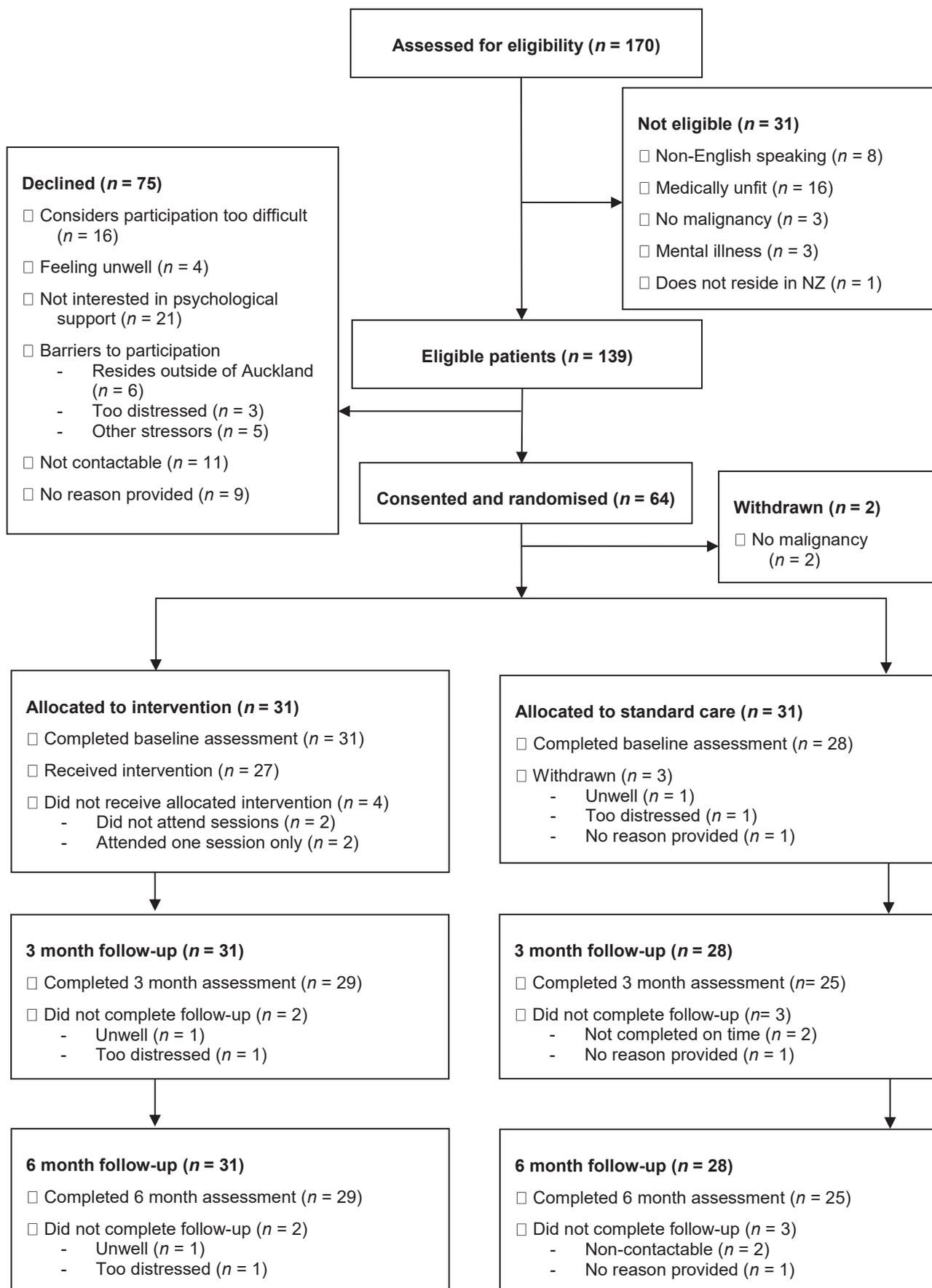


Table 21. Demographic and medical characteristics of patients assigned to the intervention compared to standard care

	Intervention Group (n = 31)	Control Group (n = 28)	Statistical Difference (χ^2)
Gender			
Male	28 (90%)	17 (61%)	7.126 ($p = .01$)
Female	3 (10%)	11 (39%)	
Ethnicity			
New Zealand European	28 (90%)	17 (61%)	9.060 ($p = .06$)
Maori	1 (3%)	7 (25%)	
Samoan	0 (0%)	1 (4%)	
Tongan	0 (0%)	1 (3%)	
Other	2 (7%)	2 (7%)	
Marital Status			
Single	2 (7%)	8 (29%)	5.462 ($p = .14$)
Married	15 (48%)	12 (43%)	
Divorced	10 (32%)	6 (21%)	
Widowed	4 (13%)	2 (7%)	
Employment			
Employed	16 (52%)	17 (61%)	5.101 ($p = .40$)
Unemployed	2 (6%)	3 (11%)	
Retired	9 (29%)	3 (10%)	
Student	1 (3%)	0 (0%)	
Beneficiary	3 (10%)	5 (18%)	
Cancer Type			
HNC	27 (87%)	28 (100%)	3.876 ($p = .11$)
Metastatic skin cancer	4 (13%)	0 (0%)	
Cancer Stage			
I-II	5 (16%)	10 (36%)	2.976 ($p = .08$)
III-IV	26 (84%)	18 (64%)	
Treatment			
Surgery	3 (10%)	9 (32%)	4.583 ($p = .03$)
Radiotherapy	28 (90%)	19 (68%)	
Modality			
Single Modality	7 (23%)	10 (36%)	1.237 ($p = .27$)
Combined Treatment	24 (77%)	18 (64%)	

With respect to the timing of intervention sessions, session one occurred on average 35 days after the multidisciplinary clinic meeting ($M = 35.34$, $Mdn = 32$, $SD = 17.24$, $Range = 72$), session two occurred on average 76 days after the meeting ($M = 76.22$, $Mdn = 70$, $SD = 23.51$, $Range = 98$), and the final session occurred an average of 120 days after the meeting ($M = 120$, $Mdn = 112$, $SD = 49.44$, $Range = 232$). When excluding one participant who had to delay the timing of intervention sessions due to unforeseen circumstances, the average number of days between the initial clinic meeting and session two ($M = 73.66$, $Mdn = 69$, $SD = 19.74$, $Range = 66$) and session three was reduced ($M = 112.65$, $Mdn = 112$, $SD = 33.43$, $Range = 163$). To provide a context for these time frames, standards of service provision require that patients referred with a high suspicion of HNC receive their first cancer

treatment within 62 days. Patients with a confirmed diagnosis of HNC receive their first treatment or alternative management within 31 days of the decision to treat.

Regarding missing data, all patients completed every item on each assessment measure at baseline ($n = 59$), with the exception of one participant who missed the timeline item of the Brief-IPQ. At 3 month follow-up, all patients completed every item on each assessment measure ($n = 54$), with the exception of one participant who again missed the timeline item, and one participant who did not complete the physical HRQL items of the FACT-H&N. At 6 month follow-up ($n = 54$), complete data were obtained from all patients, excluding one participant who missed the timeline item, and one participant who missed items on the HNC specific HRQL subscale.

Illness Perceptions

When performing intention to treat analyses, no significant differences in illness perceptions were found between patients assigned to the intervention ($n = 29$) and patients assigned to the control group ($n = 25$), at 3 and 6 month follow-up. Table 22 presents the mean change in illness perceptions from baseline to 3 and 6 months for patients who received the intervention ($n = 27$) and those who did not ($n = 27$) (per protocol analyses). There was a significant difference in perceptions of treatment control at 3 months; patients who received the intervention had a slight increase in their perceptions of treatment control, while patients who did not receive the intervention had a decrease in treatment control perceptions. Table 22 also presents the mean change in illness perceptions across time for patients distressed at baseline who received the intervention ($n = 17$) and patients who did not ($n = 16$) (subgroup analyses). The significant difference in perceptions of treatment control continued to be observed between groups at 3 months. There was also a significant difference in perceptions of concern at this time point, with patients who received the intervention reporting a greater decrease in concern relative to those who did not. This is representative of a very large effect. No other significant differences in illness perceptions were found between groups.

Table 22. Mean change in patient illness perceptions from baseline to 3 and 6 months for intervention and control group

	3 Months					6 Months				
	Intervention	Control	<i>F</i>	<i>p</i>	<i>d</i>	Intervention	Control	<i>F</i>	<i>p</i>	<i>d</i>
Per Protocol Analyses										
Consequences	-0.04 (3.11)	-0.52 (3.04)	0.12	.73	0.16	-0.85 (2.63)	-1.22 (2.89)	0.00	.95	0.13
Timeline	-1.19 (2.00)	0.11 (3.07)	2.88	.10	0.50	-0.92 (2.95)	-0.33 (3.10)	1.40	.24	0.19
Personal Control	-0.67 (4.22)	0.89 (3.48)	2.01	.16	0.40	-0.30 (3.56)	1.11 (3.47)	0.91	.35	0.40
Treatment Control	0.04 (2.08)	-0.81 (3.01)	8.40	.01	0.33	0.04 (2.64)	0.22 (2.38)	0.39	.54	0.07
Identity	0.15 (2.61)	-0.41 (3.58)	0.22	.64	0.18	0.70 (3.04)	-1.19 (2.98)	0.34	.56	0.63
Concern	-1.63 (3.75)	-0.96 (2.78)	0.75	.39	0.20	-2.59 (2.61)	-2.37 (3.85)	0.17	.69	0.06
Coherence	0.07 (2.65)	0.37 (2.20)	0.02	.88	0.12	0.15 (3.24)	0.63 (2.82)	0.41	.53	0.16
Emotional Impact	-0.07 (2.54)	-0.52 (2.53)	0.01	.91	0.18	-0.96 (2.84)	-1.56 (2.97)	0.16	.69	0.21
Subgroup Analyses										
Consequences	-0.94 (3.25)	-0.94 (3.40)	1.07	.31	0.00	-1.76 (2.56)	-2.31 (2.80)	0.23	.64	0.21
Timeline	-1.56 (2.10)	0.06 (3.02)	3.61	.07	0.62	-2.25 (2.41)	-1.25 (3.11)	2.02	.17	0.36
Personal Control	-1.06 (3.86)	1.06 (2.86)	3.29	.08	0.62	-0.24 (3.80)	1.44 (3.67)	1.50	.23	0.45
Treatment Control	0.41 (2.37)	-0.75 (3.49)	6.03	.02	0.39	0.53 (2.81)	0.00 (2.92)	1.32	.26	0.18
Identity	-0.47 (2.63)	-0.75 (3.36)	1.63	.21	0.09	0.35 (3.48)	-1.88 (2.68)	0.07	.79	0.72
Concern	-3.00 (2.89)	-0.75 (1.88)	5.86	.02	0.92	-3.06 (2.73)	-3.63 (3.36)	0.05	.82	0.19
Coherence	-0.12 (3.16)	0.69 (2.27)	0.21	.65	0.29	-0.35 (3.69)	0.75 (2.72)	0.60	.45	0.34
Emotional Impact	-0.82 (2.58)	-1.06 (2.93)	0.89	.35	0.09	-1.53 (2.48)	-2.87 (2.92)	0.00	.99	0.50

Note. Per protocol analyses - comparison is between patients who received the intervention ($n = 27$) and those who did not ($n = 27$); Subgroup analyses - comparison is between patients who received the intervention ($n = 17$) and those who did not ($n = 16$) with scores >10 on the GHQ-12 at baseline.

Health-Related Quality of Life (HRQL)

Table 23 presents the mean change in HRQL from baseline to 3 and 6 month follow-up for patients in the intervention and control group, based on intention to treat analyses, per protocol analyses, and subgroup analyses. When comparing patients assigned to the intervention ($n = 29$) and those assigned to the control group ($n = 25$), as well as patients who received the intervention ($n = 27$) with those who did not ($n = 27$), there was a significant difference in social HRQL at 6 months. Intervention participants had an increase in social HRQL from baseline to 6 months, while control participants had a decrease. This difference was also noted when comparing distressed patients who received the intervention ($n = 17$) with those who did not ($n = 16$). No other significant differences in HRQL were found between patients in the intervention and control group.

Table 23. Mean change in patient HRQL from baseline to 3 and 6 months for intervention and control group

	3 Months					6 Months				
	Intervention	Control	<i>F</i>	<i>p</i>	<i>d</i>	Intervention	Control	<i>F</i>	<i>p</i>	<i>d</i>
Intention to Treat										
Total HRQL	-4.03 (18.98)	-3.54 (21.87)	0.16	.69	0.01	4.07 (20.95)	1.60 (18.01)	1.06	.31	0.13
Physical	-1.69 (8.11)	-0.13 (5.23)	0.53	.47	0.23	0.03 (6.58)	1.36 (2.72)	0.71	.41	0.26
Social	0.24 (3.24)	-1.24 (4.26)	2.55	.12	0.39	1.17 (4.83)	-1.92 (5.42)	5.47	.02	0.60
Emotional	1.10 (3.51)	0.36 (4.70)	0.59	.45	0.18	2.48 (3.56)	1.56 (3.56)	0.96	.33	0.26
Functional	-0.10 (6.09)	-0.84 (5.70)	1.19	.28	0.13	1.31 (7.03)	0.80 (4.86)	0.59	.45	0.08
Additional	-3.59 (6.09)	-2.04 (8.98)	0.00	.96	0.20	-1.18 (8.50)	-0.20 (8.28)	0.48	.49	0.12
Per Protocol Analyses										
Total HRQL	-4.52 (17.27)	-3.08 (23.07)	0.39	.53	0.07	2.81 (20.43)	3.00 (18.89)	0.72	.40	0.01
Physical	-1.19 (7.54)	-0.77 (6.40)	0.01	.95	0.06	0.07 (6.71)	1.22 (2.94)	0.40	.22	0.26
Social	0.30 (3.33)	-1.19 (4.11)	3.11	.08	0.40	1.22 (5.00)	-1.74 (5.25)	5.98	.01	0.58
Emotional	0.85 (2.82)	0.67 (5.09)	0.47	.50	0.04	2.07 (2.72)	2.04 (4.29)	0.20	.65	0.01
Functional	-0.44 (5.91)	-0.44 (5.94)	1.09	.30	0.00	1.07 (7.21)	1.07 (4.82)	0.72	.40	0.00
Additional	-4.04 (5.47)	-1.70 (9.11)	0.04	.85	0.31	-1.88 (8.18)	0.41 (8.48)	0.32	.57	0.27
Subgroup Analyses										
Total HRQL	0.53 (15.67)	1.53 (24.96)	1.07	.31	0.04	6.44 (22.84)	9.88 (19.11)	0.25	.62	0.16
Physical	0.29 (8.18)	-0.73 (7.80)	1.81	.19	0.13	0.53 (7.74)	1.56 (3.60)	0.03	.87	0.17
Social	0.59 (3.47)	-0.75 (3.09)	2.63	.12	0.41	2.12 (5.48)	-0.06 (3.30)	4.48	.04	0.48
Emotional	1.65 (1.97)	0.94 (6.22)	1.80	.19	0.15	2.24 (2.14)	3.44 (4.68)	0.02	.88	0.33
Functional	1.65 (5.57)	-0.13 (6.44)	3.68	.07	0.30	2.41 (7.90)	0.81 (6.09)	3.64	.07	0.23
Additional	-3.65 (5.14)	1.31 (8.94)	0.05	.83	0.68	-1.44 (9.66)	4.13 (7.38)	0.07	.79	0.65

Note. Intention to treat - Comparison is between patients assigned to the intervention group ($n = 29$) and patients assigned to the control group ($n = 25$); Per protocol analyses - comparison is between patients who received the intervention ($n = 27$) and those who did not ($n = 27$); Subgroup analyses - comparison is between patients who received the intervention ($n = 17$) and those who did not ($n = 16$) with scores >10 on the GHQ-12 at baseline.

Distress

When comparing patients in the intervention and control group (using intention to treat, per protocol analyses, and subgroup analyses), no significant differences in distress were found at 3 or 6 month follow-up.

Analyses on illness perceptions, HRQL, and distress were also performed when including gender and radiotherapy treatment as covariates due to significant differences between groups at baseline. This did not make a difference to the statistical significance of the results found.

Intervention Feedback

Twenty-five of 27 participants who completed open-ended questions about the intervention reported being satisfied with the sessions that they received; an example comment was, “Very satisfied. Just the right number of sessions during a trying time”. Aspects of the intervention that were considered most beneficial included discussing HNC (“Being able to talk about the issues of having cancer”) and treatment (“Getting one to talk about all aspects of treatment and feelings”), having someone to listen (“The positive reception and compassionate listening made the experience”), and learning coping strategies/stress reduction (“Thinking about coping strategies”, “Being stress free about my mortality”). The majority of patients suggested no changes to the intervention were necessary (75%), although one patient suggested that group sessions could be helpful, one patient would have liked more individual sessions, and two patients suggested that the intervention could be started earlier (“An earlier start as preparation for what is to follow”). Twenty-five participants (93%) would recommend the intervention to others diagnosed with HNC.

Discussion

This is the first pilot RCT to investigate the effectiveness of a brief psychological intervention targeting illness perceptions in newly diagnosed patients with HNC. Results found that patients who received the intervention in addition to standard care had improved perceptions of treatment and social HRQL over time in comparison to patients who received standard care alone. Improvements in social HRQL continued to be observed when conducting intention to treat comparisons. These preliminary findings suggest that self-regulatory interventions based on the CSM may have particular utility at improving social functioning following HNC diagnosis and treatment.

Further support for the intervention was found when restricting analyses to patients who exhibited distress at diagnosis. Distressed patients who received the intervention reported a decrease in perceptions of concern from baseline to 3 months, while perceptions of treatment control increased during this time. These participants also had a greater increase in social HRQL from baseline to 6 months compared to participants who received standard care alone. The importance of delivering psychological interventions to sufficiently distressed patients has been identified in the literature (Luckett et al., 2011). Not only does this increase power to detect intervention effects but ensures that research findings are generalisable to clinical practice, where guidelines recommend psychological support specifically for patients experiencing heightened distress (NCCN, 2011). Other studies have found that after targeting psychological interventions to HNC patients experiencing distress, significant improvements in depression, anxiety and post-traumatic stress (Kangas et al., 2013), and smoking cessation (Duffy et al., 2006) can be achieved. It is important to note that patients classified as distressed for the purpose of this study were experiencing a subclinical distress level. Therefore, the results may not be comparable to the results of other studies targeting patients with distress, and it is unclear whether the same benefits of the intervention would be observed among patients meeting clinical criteria. Nevertheless, there is evidence that treating subclinical distress can have positive implications in the long-term, with psychological treatment of subclinical depression related to a reduced incidence of major depressive episodes 6 and 12 months later (Cuijpers et al., 2014).

The self-regulatory intervention tested is the first to be provided at time of diagnosis and throughout treatment among patients with HNC. The low rates of participant dropout suggest that it is feasible to provide psychological support to patients during this time, particularly if the delivery of this support is flexible and coordinated around patient medical appointments and treatment side effects. Responses to open-ended questions regarding satisfaction with the intervention suggest that patients appreciated that the intervention was delivered soon after diagnosis, consistent with other research that HNC patients would like psychological support to manage this time (Richardson et al., 2015b). Indeed, diagnosis and treatment are times at which patients with HNC report high levels of psychological distress (including depression and anxiety) (Haisfield-Wolfe et al., 2009), and reduced HRQL (Howren et al., 2013), suggesting that this may be the most beneficial time to intervene. Other studies have found that patients are dissatisfied with the amount of information they receive regarding the long-term impact of HNC and treatment (Ziegler et al., 2004) and that this can influence their subsequent experience of distress (Llewellyn et al., 2006b). Therefore, psychological interventions

provided early after diagnosis may be an effective way to provide information and prepare patients for what is ahead, with positive implications for psychological adjustment.

Providing psychological support early after diagnosis was found to benefit patient social HRQL in the present study. Health-related quality of life is a particularly important outcome in patients with HNC, for whom dry mouth, difficulty swallowing, speech difficulties, pain, and negative changes in appearance can be enduring problems following treatment (Abendstein et al., 2005). Efforts to improve social HRQL among patients with HNC are essential considering that the social impact of the disease is of great importance to this population (Ramirez et al., 2003). In a study of 62 patients surgically treated for laryngeal cancer, patients did not consider the permanent stoma and voice loss to be the most important contributors to their quality of life, but instead reported that work and family relationships were the domains with the poorest adjustment (Ramirez et al., 2003). Furthermore, social functioning is an aspect of HRQL that is most negatively affected by HNC. Not only do common side effects such as facial disfigurement provoke a range of negative reactions from others, but changes in patient self-esteem and sense of self can influence desire to engage in social interactions (Fingeret, Teo, & Goettsch, 2015). Other side effects, including difficulties with chewing, swallowing, and speaking, can make it very hard for patients to engage in regular social activities with their family and friends, and often negatively impact on communication. In fact, research has found that patients with HNC are at risk of social isolation and disrupted relationships given that the ability to eat and speak is what allows us to participate in a diverse range of social interactions (Gamba et al., 1992).

Our findings can be compared to those reported by other studies that have aimed to provide information and coping strategies to patients with HNC, although these have used less robust methods. In a study by Semple and colleagues (2009), 54 successfully treated HNC patients screening positive for distress self-selected to participate in a problem-focused intervention or to usual care. Patients who received the intervention demonstrated improvements in depression and anxiety from baseline to 3 months, as well as improved social functioning and quality of life compared to patients in the usual care group. However, self-selection may have biased these results. Similarly, a non-randomised study found that a short-term coping strategies intervention improved physical and social functioning, global quality of life, fatigue, and depressive symptoms in HNC patients 1-36 months post-treatment (Allison et al., 2004). The present study adds to the literature by using a randomised controlled design. The results provide support for the ability of psychological interventions to improve social HRQL in patients with HNC, although results for other outcomes were not as strong.

Overall HRQL and distress were not improved in patients who received the intervention, an unexpected finding. It may be that social HRQL is more amenable to change than overall HRQL which incorporates physical and head and neck specific functioning. These domains are likely to be strongly influenced by medical factors, including cancer stage, treatment type, and symptom severity. In contrast, social HRQL may have been improved by the discussion and implementation of coping strategies to manage side effects of treatment and the distress that these can cause. With respect to patients' emotional experience of the disease, it is possible that the intervention was too brief to change or impact distress levels. It may also be that patients who were most distressed at the time of diagnosis (and who had the greatest room for improvement in depression and anxiety) were less likely to take part than other patients. The participation rate of the present study was 46%, consistent with low rates of participation in other intervention studies involving patients with HNC (Duffy et al., 2006; Ostroff et al., 2004) and male cancer patients more generally (Berglund et al., 2007). Therefore, it is possible that a significant proportion of patients may not engage in an intervention involving sessions with a psychologist were it to be incorporated into clinical practice.

The rate of caregiver participation in the study was particularly low. This is likely because the majority of patients who volunteered were single. It may be that these patients perceived a greater need for psychological support than those who were already supported by a spouse. Nevertheless, caregivers who were assigned to the intervention group demonstrated good adherence to the sessions suggesting that they had a desire to be involved and to receive support. This is consistent with other findings demonstrating that caregivers of patients with HNC perceive a need for psychological assistance (Baghi et al., 2007). Despite the study being underpowered to examine caregiver outcomes, it is plausible that their inclusion in the intervention sessions may have contributed to positive changes in social HRQL among patients. Specifically, changes may reflect an increase in the similarity of patient and caregiver perceptions in response to the intervention, which has previously been related to better HNC patient HRQL (Richardson et al., 2016a).

Patient adherence to the intervention was high. This is worth highlighting given that a number of previous studies examining interventions for patients with HNC have had high rates of participant dropout, particularly those which have required participants to attend multiple sessions within a pre-specified time frame. These interventions may not benefit the majority of HNC patients because the burden of participation is too great. This is particularly so during treatment where survival is of primary concern among patients and their family members. The findings of this RCT suggest that an

intervention consisting of three face-to-face sessions with a health psychologist poses minimal patient burden. Furthermore, such a brief intervention may be practically incorporated into clinical practice, presenting an opportunity to improve HNC patient psychological outcomes.

While strengths of this study include the use of a randomised controlled design and high acceptability of the intervention among recipients, there are several important limitations to consider. First, no active control group was used. Therefore, it is difficult to determine whether improvements observed in patients who received the intervention are attributable to the content of the sessions or are instead a result of non-specific factors, such as the therapeutic relationship. Furthermore, the study was not restricted to patients experiencing distress. Consequently, a number of participants who were well-adjusted received the intervention, diluting power to detect significant effects. Statistical power was also limited by the small sample size overall in this pilot study. Based on a power calculation, the desired sample size was 68 patients, yet only 54 were included in the final analyses. As a result, it is possible that the results obtained may not reflect what would have been observed had the goal sample size been achieved. It is also difficult to determine whether the results would generalise to the wider HNC patient population. Although there was little missing data, missing responses to questionnaire items may have altered the study findings. Additionally, investigations of the impact of the intervention on caregiver adjustment were not performed, due to the low rate of caregiver participation. Finally, the researchers were not blind to group condition which can result in biased estimates of treatment effects. However, questionnaires were completed in the absence of the researchers and the psychologist who delivered the intervention was not involved in data collection.

The results demonstrate that it is feasible to deliver a brief intervention to patients with HNC early after diagnosis and during treatment, and that this can improve patient perceptions of treatment control and concern (particularly among those who are distressed), and improve social HRQL. Larger replication studies targeted to patients experiencing high levels of distress at HNC diagnosis are needed.

Chapter 10. Discussion

Overview

Head and neck cancer is a complex and challenging disease associated with detriments in a wide range of basic human functions, including the ability to breathe, speak, and swallow. These detriments, in addition to severe facial disfigurement in the head and neck region, are often experienced by patients as a consequence of their treatment (which may involve any combination of surgery, radiotherapy, and chemotherapy). The side effects of HNC and its treatment have been found to cause enduring impairments in patient physical, social, and emotional wellbeing. Psychological distress is prevalent among patients, with high rates of depression and anxiety documented across the disease trajectory. The difficulties experienced by patients with HNC also affect the mental health of their caregivers, who report significant anxiety, strain, and burden. The unique challenges that accompany HNC, and the implications these have for both patient and caregiver wellbeing, necessitate research to identify factors that contribute to variation in physical and psychological responses to the disease.

While several studies have examined the contribution of disease-specific variables (including cancer stage, treatment modality, and symptom severity) to HNC patient outcomes, few have considered the potential influence of psychological factors. The results of research involving patients with other illnesses and preliminary evidence from studies of patients with HNC suggest that perceptions of the disease, as well as strategies used to cope, may contribute to HRQL and psychological wellbeing. However, few studies have examined the predictive capacity of these variables at time of diagnosis, and whether they may also be important to consider among HNC caregivers. Furthermore, evidence for psychological interventions that can improve overall adjustment to HNC is limited, with caregivers yet to be incorporated into such interventions. Therefore, this thesis had two aims. The first was to determine whether illness perceptions and coping at HNC diagnosis could predict variation in patient and caregiver psychological outcomes at this time point and again 6 months later. The second was to examine whether a brief psychological intervention targeting illness perceptions and coping could improve patient HRQL, as well as patient and caregiver psychological wellbeing.

In this discussion, the key findings of the thesis are first summarised. Next, the findings are considered within the broader literature examining factors that contribute to HNC patient and caregiver adaptation, with a particular focus on studies that have investigated the role of illness perceptions and coping. Findings are also contextualised within available research on psychological interventions for individuals affected by HNC. The clinical implications of the studies presented in this thesis are then described. Finally, limitations of the studies are identified and directions for future research are provided.

Summary of Key Findings

Two studies were conducted to achieve the aims of this thesis. The first investigated relationships between illness perceptions, coping, and psychological outcomes over time, using an observational prospective design. Questionnaires were completed by patients and their caregivers at time of diagnosis and again 6 months later. Overall, the results from this study supported Leventhal's (1980) CSM as a useful framework for understanding variation in responding to HNC. The second study employed a pilot randomised controlled design to examine the feasibility and effectiveness of an intervention to modify illness perceptions among patients with HNC and their caregivers. The results demonstrated that patients and caregivers will adhere to such an intervention delivered early after diagnosis and during treatment, and that the intervention had positive implications for patient social HRQL.

Five manuscripts were published from Study 1. The first reported cross-sectional analyses of patient and caregiver illness perceptions, as presented in Chapter 3 (Richardson et al., 2015a). Both patients and caregivers were found to hold unique representations of HNC, with caregivers significantly more negative than patients with respect to the consequences, timeline, and treatment of the disease. They also perceived greater concern and a stronger emotional impact than patients. Interactions between patient and caregiver illness perceptions were related to different dimensions of patient HRQL. Scores on this outcome tended to be lowest when caregiver perceptions reflected greater negativity relative to patient perceptions. For example, patient social HRQL was lowest when caregivers had long timeline perceptions yet patient timeline perceptions were short. These findings highlighted the importance of considering the contribution of not only patients' own perceptions to their physical and psychological wellbeing, but also the perceptions of their caregivers.

The second manuscript presented in Chapter 4 documented longitudinal associations between patient and caregiver illness perceptions, revealing that dissimilarities at diagnosis were related to patient HRQL at 6 month follow-up (Richardson et al., 2016a). Specifically, greater discrepancy in patient and caregiver perceptions of timeline, personal control, and illness identity predicted lower patient HRQL scores, even when controlling for patient and caregiver individual perceptions and patient HRQL at baseline. Therefore, results suggested that reducing discrepancies between patient and caregiver perceptions at time of HNC diagnosis could be an effective way to promote patient HRQL following treatment.

The third manuscript in Chapter 5 examined patient coping behaviours. Patients who engaged in self-blame at diagnosis were more likely to report low HRQL 6 months later (Richardson et al., 2016b). Furthermore, use of self-blame, denial, and behavioural disengagement at this time predicted greater PTSD symptomology. The results of study 1 highlighted the considerable prevalence of PTSD among patients *and* caregivers 6 months after HNC diagnosis. This outcome had previously received limited attention in the context of HNC, despite the threatening nature of the disease.

Chapter 6 presented the fourth manuscript from Study 1, and showed that the illness perceptions and coping strategies of caregivers at diagnosis were related to their experience of PTSD at 6 months (Richardson et al., 2016c). Perceptions of low treatment control and a strong illness identity, and use of avoidant coping, were related to a greater number of PTSD symptoms. Collectively, the results suggested that psychological interventions addressing inaccurate perceptions of HNC and maladaptive coping strategies at diagnosis may help to promote psychological wellbeing and reduce PTSD among both patients and their caregivers.

Chapter 7 comprised the final manuscript from Study 1, which documented HNC patient and caregiver perspectives on social and psychological support, including whether they thought formal psychological support would be beneficial (Richardson et al., 2015b). Approximately 40% of patients and caregivers stated that they would appreciate such support, and specified that face-to-face sessions with a psychologist could be delivered early after diagnosis. Both patients and caregivers desired more information about what to expect from the disease, as well as strategies that could be used to cope with treatment and the distress that this can cause. These findings, in addition to the previously documented findings of Study 1 and those obtained in other patient populations, informed the development of Study 2.

Study 2 was a pilot RCT designed to compare the effectiveness of a self-regulatory intervention to standard care, as described in Chapter 9 of this thesis. The self-regulatory intervention was delivered by a health psychologist, and involved three sessions occurring early after diagnosis and across treatment. Patients who received the intervention had an increase in perceptions of treatment control, as well as an increase in social HRQL, relative to patients in the standard care group.

Integration with Broader Literature

This thesis makes four major contributions to the HNC literature, including the identification of: 1) longitudinal relationships between illness perceptions, coping, and psychological outcomes among patients and their caregivers; 2) the importance of caregiver illness perceptions to patient illness perceptions and patient psychological outcomes; 3) patient and caregiver social and psychological support needs; and 4) the feasibility and effectiveness of a self-regulatory intervention designed to improve patient HRQL, and patient and caregiver psychological wellbeing. Each of these contributions, and their place within the existing literature, are discussed in turn.

Illness Perceptions, Coping, and Outcomes

The results of this thesis suggest that the CSM can be used to identify HNC patients and their caregivers who may be at increased risk of poor psychological outcomes following diagnosis. Both illness perceptions and coping were associated with aspects of patient and caregiver psychological wellbeing, and these relationships were observed over time. Such findings are in line with a small but growing literature demonstrating that illness perceptions and coping strategies can predict outcomes in patients with HNC (Dempster et al., 2011b; Llewellyn et al., 2007b; Scharloo et al., 2010).

Negative perceptions of HNC at diagnosis were related to lower patient HRQL at this time point and again 6 months later. Specifically, patient perceptions of many negative consequences and a strong illness identity (many symptoms) were associated with worse HRQL (Richardson et al., 2015a). Other cross-sectional studies have also linked negative perceptions of illness identity and emotional impact to low HNC patient HRQL (Scharloo et al., 2005), in addition to perceptions of a long timeline (Llewellyn et al., 2007a). Furthermore, perceptions of many consequences and a long timeline at HNC diagnosis have been found to predict lower HRQL as well as worse functioning and reduced global health 2 years later (Scharloo et al., 2010). However, these longitudinal findings are yet to be replicated; the longitudinal investigation of patient illness perceptions in this thesis involved

comparisons with caregiver perceptions and did not consider patient perceptions alone. Only two other longitudinal studies of illness perceptions have been conducted in patients with HNC, both of which report results relating to distress rather than HRQL (Dempster et al., 2011b; Llewellyn et al., 2007b). Therefore, further research will be necessary to confirm the significance of illness perceptions to HNC patient HRQL over time.

The strategies patients used to cope at diagnosis were associated with their psychological outcomes 6 months later (Richardson et al., 2016b). Blaming oneself for the HNC diagnosis predicted lower subsequent HRQL, while self-blame, behavioural disengagement, and use of denial predicted a higher number of PTSD symptoms. Several other studies have related coping strategies to HNC patient HRQL, although almost exclusively in the post-treatment phase (Dunne et al., 2016). Furthermore, studies have most consistently demonstrated relationships between the use of avoidant coping strategies and reduced patient HRQL (Aarstad et al., 2011a; Eadie & Bowker, 2012; Horney et al., 2011), rather than self-blame. This may be because available research is predominantly cross-sectional in nature, with only two studies examining longitudinal associations between coping at diagnosis and future outcomes (Derks et al., 2004; Llewellyn et al., 2007b). It might be that while avoidant coping strategies have strong direct relationships with patient HRQL scores, self-blame is a better predictor of this outcome over time. Indeed, Llewellyn et al. (2007b) found that engaging in self-blame at HNC diagnosis was associated with higher patient depression 6-8 months post-treatment.

This thesis is the first to identify associations between patient coping strategies at time of HNC diagnosis and future PTSD symptoms. It is perhaps not surprising that use of behavioural disengagement and denial predicted PTSD, given that avoidance is a key feature of the disorder. Nevertheless, the longitudinal design of Study 1 made it possible to investigate temporal relationships, and identified that avoidant coping behaviour preceded PTSD symptomology. This is consistent with research involving individuals who have experienced trauma (Bryant & Harvey, 1995), and other patient populations (Bryant, Marosszeky, Crooks, Baguley, & Gurka, 2000; Otis et al., 2003), which has highlighted that avoidant coping can predict subsequent PTSD development as well as symptom severity. Self-blame was also a unique significant predictor of HNC patient PTSD. Several studies have shown that self-blame is related to increased self-focused attention, negative self-evaluation, and depression (Frisch, 1998), with these results observed in individuals with lung, breast, and prostate cancer (Else-Quest et al., 2009). Therefore, negative changes in self-perception may explain the

observed association between self-blame and increased susceptibility to PTSD among patients with HNC.

Caregivers of patients with HNC were found to form their own individual representations of the disease (Richardson et al., 2016c). Caregiver illness perceptions were consistently more negative than patient perceptions, in line with research involving caregivers of other patient groups (Kaptein et al., 2007; Karademas et al., 2010; Searle et al., 2007; Twiddy et al., 2012), including caregivers of patients with oesophageal cancer (Dempster et al., 2011a). Furthermore, both illness perceptions and coping strategies at diagnosis predicted caregiver PTSD symptom level at 6 month follow-up. Perceiving a high number of patient symptoms and low treatment control was related to greater future PTSD, in addition to the use of denial, behavioural disengagement, and humour. Dempster and colleagues (2011c) found different perceptions to be of relevance to oesophageal cancer caregiver distress, including perceptions of consequences, personal control, and coherence. This may be because the study was conducted among caregivers of patients at varying stages post-treatment. It is possible that perceptions of identity and treatment control are stronger predictors of caregiver psychological wellbeing earlier in the disease trajectory when HNC symptoms and treatment side effects are most severe. Alternatively, it may be that perceptions most strongly related to distress differ to those linked to PTSD, a more severe and debilitating disorder.

Other research involving caregivers of patients with HNC has found relationships between avoidant coping and caregiver distress levels. For example, attempting to divert thoughts away from the disease has been related to greater depression and anxiety among oesophageal cancer patient caregivers (Dempster et al., 2011c). Similarly, spouses of HNC patients who used a passive style of coping in the post-treatment phase reported greater distress (Verdonck-de Leeuw et al., 2007). This coping style is characterised by avoidance, withdrawal, and wishful thinking. Therefore, evidence suggests that coping characterised by avoidance is particularly detrimental to HNC caregiver psychological wellbeing. However, the dearth of studies in this area is concerning, given that the prevalence of distress and PTSD among caregivers of patients with HNC may be even higher than that documented among patients (Longacre et al., 2012). Posluszny and colleagues (2014) reported that almost 30% of caregivers met criteria for estimated PTSD soon after HNC diagnosis, compared to 12% of patients. Comparable rates of PTSD were found among patients and their caregivers in this thesis, with 19% reporting scores indicative of the disorder at 6 month follow-up.

Caregiver Illness Perceptions and Patient Outcomes

The illness perceptions of caregivers had a significant impact on patient HRQL, both cross-sectionally and longitudinally (Richardson et al., 2015a; Richardson et al., 2016a). At diagnosis, caregiver perceptions were found to moderate associations between patient illness perceptions and aspects of patient HRQL, including emotional, social, functional, physical, and head and neck specific wellbeing. In several instances caregiver perceptions augmented the effect of the patient's own perceptions on HRQL, while in other instances caregiver perceptions served to mitigate the effect. These findings are similar to those documented in the only other study examining HNC patient and caregiver illness perceptions (Dempster et al., 2011a). This cross-sectional investigation found that caregiver perceptions of coherence and consequences moderated the effect of patient perceptions on patient depression and anxiety following treatment. Studies involving other patients, including individuals with Huntington's disease, rheumatoid arthritis, diabetes, CFS, and AD have also demonstrated relationships between caregiver illness perceptions, patient illness perceptions, and patient health-related behaviour and psychological wellbeing (Heijmans et al., 1999; Kaptein et al., 2007; Searle et al., 2007; Sterba et al., 2008). Such results support the CSM, which proposes that patients will develop illness representations using information from the environment, including that communicated by close others (Diefenbach & Leventhal, 1996).

Cross-sectional investigation of HNC patient and caregiver illness perceptions highlighted that discrepancies between these perceptions were frequently related to low patient HRQL. For example, when patient and caregiver perceptions of coherence were dissimilar patients reported lower total HRQL compared to when these perceptions were similar. Other studies have also demonstrated a negative impact of illness perception discrepancy on patient outcomes. Twiddy et al. (2012) found that differences in patient and caregiver perceptions of stroke were related to both patient and caregiver distress, albeit at different time points. Conversely, similar positive perceptions of illness identity, consequences, timeline, and treatment control between MI patients and their caregivers have been related to better patient recovery over time, including improved physical, psychological, and sexual functioning, lower levels of disability, and greater dietary changes (Figueiras & Weinman, 2003).

An increasing number of statistical techniques are available to examine relationships between patient and caregiver perceptions of illness, including the contribution of discrepancies to patient outcomes. One model that incorporates such statistical techniques is the APIM (Cook & Kenny, 2005).

The APIM allows for exploration of dyadic relationships while simultaneously accounting for interdependence of the variables under investigation. Given evidence for the importance of discrepancy between patient and caregiver illness perceptions, the APIM was used to investigate associations between discrepancy in perceptions at HNC diagnosis and patient HRQL 6 months later. Discrepancy was indeed related to patient HRQL, with dissimilarity in perceptions of timeline, personal control, and illness identity related to lower future HRQL. This study was the first to explore HNC patient and caregiver perceptions over time, demonstrating that the degree of match between certain perceptions can have long-term implications for patient physical and psychological functioning.

Discrepancies between the illness perceptions of patients with HNC and their caregivers largely arose from greater negativity in caregiver perceptions. Caregiver perceptions may be more negative because they have a more accurate understanding of the disease than patients, who have a tendency to form self-protective beliefs (Jemmott et al., 1986). However, there are also important differences in the roles of patients and caregivers that may lead to corresponding differences in their perceptions of HNC. The results of qualitative studies suggest that HNC caregivers perceive providing patients with emotional and practical support as their responsibility (Balfe et al., 2016a; Nund et al., 2014). They simultaneously report an inability to relieve and comprehend the patient's physical suffering, as well as overwhelming psychological distress that interferes with their capacity to provide care (Schaller, Leidberg, & Larsson, 2014).

Differences in illness perceptions between patients and caregivers may have deleterious effects on patient outcomes through their association with coping. According to the CSM, illness perceptions guide the selection of coping behaviours adopted to manage an illness. When patients and caregivers hold vastly different models of the same illness, they are likely to use different strategies to cope. These strategies may conflict with one another, leading to disagreements and reductions in feelings of intimacy and closeness (Li & Loke, 2014). Furthermore, differences in perceptions may lead to caregivers providing inappropriate support to patients as the support deemed most beneficial by the caregiver may be different to the support that the patient desires. This, in turn, may have a negative impact on patient health and wellbeing.

Patient and Caregiver Support Needs

The qualitative results of Study 1 found that patients with HNC and their caregivers have unique social and psychological support needs (Richardson et al., 2015b), reinforcing previous findings in this group (Lang et al., 2013). Patients reported relying heavily on their caregivers for support to manage the physical and emotional impacts of the disease. The types of support that patients desired from their caregivers largely matched up with those identified by caregivers as most important, including empathy and practical support. This match is necessary if social support is to have a positive impact on patient outcomes (Mathieson, Logan-Smith, Phillips, MacPhee, & Attia, 1996). To date, research findings are equivocal regarding the benefits of social support for HNC patient wellbeing (Howren et al., 2013). For example, one study documented that while *available* support was associated with lower patient depressive symptomology, *received* support was associated with higher depressive symptomology (de Leeuw et al., 2000). Interestingly, this pattern of results was strongest in patients who were not severely impacted by the disease. Patients who experience significant pain and dysfunction, particularly with respect to eating, breathing, and speaking, are likely to depend more heavily on receiving support from their caregivers to perform activities of daily living, as is indicated by other qualitative studies (Moore, Ford, & Farah, 2014a; Oskam et al., 2013).

The types of support that patients sought from their family members and friends differed to the support they perceived to be most helpful from health care professionals. Specifically, patients and caregivers wanted clinical staff to provide accurate and honest information about the HNC diagnosis, while at the same time maintaining positivity and conveying empathy. Many patients did not anticipate the extent of the functional impairments that resulted from treatment, reporting that they would have preferred to receive more information earlier in the disease trajectory. Previous studies have also identified that HNC patients and caregivers would appreciate more information regarding the consequences of their treatment (Happ et al., 2004). In particular, patients and caregivers report receiving inadequate information relating to the eating difficulties and loss of speech that often occur following HNC surgery (Lennie, Christman, & Jadack, 2001; Zeine & Larson, 1999).

A significant proportion of HNC patients and caregivers (approximately 40%) stated that they would appreciate the opportunity to address psychological concerns with a professional. Such support was desired in the form of face-to-face sessions provided early after diagnosis and during treatment. Participants wanted to receive individualised information and coping strategies, as well as an

opportunity to freely express their emotions while discussing personal fears and concerns. Although research suggests that patients with cancer as a whole perceive a need for more information, greater psychological support, and assistance in the domains of physical and daily living (Sanson-Fisher et al., 2000), requests for information and coping strategies may be particularly important to address among patients with HNC. These patients feel that current standards of information provision do not adequately prepare them for the long-term physical, psychological, and social sequelae of their disease (Ziegler et al., 2004). Furthermore, coping strategies have been identified as essential to the management of emotional responses to HNC, including anxiety and claustrophobia induced by the stabilisation mask used for radiotherapy (Moore, Ford, & Farah, 2014b), as well as treatment side effects of pain, fatigue, difficulty swallowing, problems eating and breathing, and disfigurement (Dropkin, 1999; Moore et al., 2014a).

Psychological Interventions

Study 2 provided preliminary support for a brief psychological intervention targeting illness perceptions and coping among patients with HNC and their caregivers. Results of this pilot RCT found that patients who received a self-regulatory intervention in addition to standard care had an increase in their perceptions of treatment control from diagnosis to 3 month follow-up relative to patients who received standard care alone. They also reported enduring improvements in social HRQL, with higher scores than control group patients at both 3 and 6 month follow-up. When considering patients who were distressed at diagnosis, an additional reduction in concern was observed among those in the intervention group. Analyses were not performed to investigate effects of the intervention on caregivers due to insufficient statistical power.

Despite several calls for the investigation of psychological interventions to reduce the high rates of distress among patients with HNC (Bjordal & Kaasa, 1995; Howren et al., 2013; Humphris & Ozakinci, 2006), only four other RCTs have been conducted in this group. In the largest RCT to date, Duffy and colleagues (2006) found no effect of CBT on HNC patient depression, although declines in smoking behaviour were observed. Conversely, Kangas et al. (2013) found that CBT delivered across the course of radiotherapy reduced the percentage of HNC patients meeting clinical or subclinical criteria for PTSD, anxiety, and/or depression by 12 month follow-up, although rates of participant dropout were high. Psychoeducation increased knowledge, reduced body image disturbance, and lowered anxiety in a small sample of patients with oral cancer, with a trend towards improved wellbeing

also observed (Katz et al., 2004a). Finally, a six week psychoeducation intervention that addressed patient illness perceptions and coping strategies resulted in reduced fear of cancer recurrence and anxious preoccupation among post-treatment patients with HNC (Humphris & Rogers, 2012). However, these results were not maintained over time and participant adherence to the intervention was poor. Only three of the four trials described reduced patient depressive symptoms. Collectively, the results suggest that it is difficult to develop psychological interventions that have an enduring impact on HNC patient psychological wellbeing.

The self-regulatory intervention tested was also ineffective at reducing patient depression and anxiety. This may be attributable to the brief duration of the intervention. It is possible that three sessions is an insufficient period of time in which to develop alternative methods for thinking about and coping with HNC. Although perceptions of treatment control were modified, this change was not sustained at final follow-up, and it is likely that changes in other perceptions would be necessary to produce changes in psychological wellbeing. However, it was important to investigate an intervention that placed minimal burden on patients, particularly given that the two other studies delivering an intervention across HNC treatment reported high rates of participant dropout, with many patients not capable of completing all intervention sessions due to poor health and fatigue (Kangas et al., 2013; Pollard et al., 2016).

Other self-regulatory interventions of brief duration have proven effective at improving both physical and psychological outcomes in a broad range of patient groups, including patients affected by MI, psoriasis, renal disease, asthma, and diabetes (Broadbent et al., 2009b; Fortune et al., 2004; Karamanidou et al., 2008; Keogh et al., 2011; Petrie et al., 2002; Petrie et al., 2012). This may be a result of the very different challenges faced by these illness populations and patients with HNC. In contrast to patients with other chronic conditions, HNC patients contend with multiple treatments that are each associated with their own unique, painful, and often debilitating side effects. Furthermore, long-term impairments in breathing, speaking, and appearance often limit the capacity of patients to engage in social situations and other enjoyable activities. For example, many patients must adjust to a life of eating without satisfaction as a consequence of losing the ability to chew or taste (Ottosson, Laurell, Olsson, 2013). For others, loss of speech severely interferes with the ability to communicate with others, and with the quality of personal relationships as a result (Nund et al., 2014). Physical and functional impairments resulting from HNC can also lead to dramatic changes in self-image and, consequently, sense of identity (Fingeret et al., 2015). Each of these experiences contributes to patient

psychological distress and may not necessarily be altered with psychological interventions, particularly those comprised of just a few sessions. Longer interventions may be important in the context of HNC if they are to mitigate the negative and often traumatic experiences associated with treatment and recovery (Howren et al., 2013).

The RCT conducted for this thesis was the first with the aim to improve HNC patient HRQL. Although the intervention did not modify global HRQL, the improvements observed in patient social HRQL are significant. This is a domain in which HNC patients consistently report difficulties (Hammerlid et al., 2001; Terrell et al., 2004), particularly those who undergo a laryngectomy and lose the capacity to speak. High levels of concern about socialising remain evident among patients more than 1 year after their operation (Happ et al., 2004). There is also evidence that HNC patients consider social functioning to be of greatest importance to their overall wellbeing. In a study examining HRQL concerns among patients who had head and neck surgery and their clinicians, clinicians ranked communication impairment as the top concern of patients, whereas patients ranked physical consequences and interference with social activities as most important (Mohide et al., 1992). Research also suggests that factors indicative of good social function, such as open discussion with family, are associated with positive rehabilitation outcomes for patients with HNC, including better physical and psychological adjustment (Babin et al., 2008; de Boer et al., 1995).

Other studies have documented improvements in HRQL in response to psychological interventions for patients with HNC, although methodological problems prevent strong conclusions from being drawn. For example, Semple et al. (2009) found that HNC patients experiencing significant psychosocial dysfunction who self-selected to receive a CBT intervention reported a reduction in depression and anxiety, and improvements in social functioning and global quality of life, compared to those who self-selected into a standard care control group. Studies using more rigorous designs and larger samples have not found the same HRQL benefits. In a longitudinal case-controlled study comparing 52 patients who received psychoeducation in addition to standard care with 92 patients who received standard care alone, intervention participants reported significantly lower HRQL scores 1 year after diagnosis (Peterson et al., 2003). High levels of depression remained a problem for both groups. Therefore, the use of a robust randomised controlled design may explain why only modest differences in HRQL were observed in response to the self-regulatory intervention tested in this thesis.

It is important to consider whether the RCT was adequately powered to detect changes in HNC patient psychological outcomes in response to the intervention. The participation rate was 46%, with a total of 64 patients consenting to take part. This is comparable to the low rates of participation documented in other intervention studies involving patients with HNC (Duffy et al., 2006; Kangas et al., 2013; Schnoll et al., 2005). The number of caregivers that participated was particularly low, with only 28% of patients nominating a caregiver to take part in the study. One reason for this is that the majority of participants did not have a spouse or partner. These patients likely perceived a greater need for psychological support than patients who were married and well-supported by family and friends. The burden associated with HNC treatment may be another factor that contributed to the low rate of participation. Several patients reported declining to participate because they perceived participation to be too difficult in conjunction with other specialist appointments, treatment sessions, and the experience of painful symptoms. However, it is also possible that patients declined to take part due to negative perceptions regarding psychological support. Patients with HNC less frequently express a desire for support from psycho-oncologists, and less frequently receive such support, compared to patients with other types of cancer (Singer et al., 2012). This may be because patients are unaware of the role of psychologists in HNC care, and that these individuals can provide support to manage and adapt to physical illness. Integration of a psychologist into the HNC multidisciplinary team could help to change these views by ensuring that psychological support is routinely offered to all patients, normalising the service and increasing uptake as a result.

Although the rate of participation was low, there were low levels of participant dropout throughout the study period. This is a strength of the study and contrasts with others to date, particularly those which have endeavoured to provide support during treatment (Kangas et al., 2013; Pollard et al., 2016). The low dropout rate may be attributable to the individual tailoring of intervention content and the flexibility of session times. Importantly, participants reported high satisfaction with the intervention after completion.

Clinical Implications

The findings presented in this thesis have several clinical implications. First, the identification of longitudinal relationships between illness perceptions, coping, and psychological outcomes among patients with HNC and their caregivers provides a rationale for screening and detecting individuals who hold maladaptive models of the disease. Head and neck cancer patients who perceived many

consequences and a strong illness identity at diagnosis reported significantly reduced HRQL, while caregivers who perceived a strong identity and low treatment control experienced higher subsequent PTSD symptomology. Previous systematic reviews and meta-analyses have documented that negative perceptions of consequences, identity, and control place individuals at greatest risk of poor outcomes, predicting lower levels of psychological wellbeing, vitality, and social and physical functioning across diverse patient populations (Broadbent et al., 2015; Hagger & Orbell, 2003), including patients with cancer (Richardson et al., 2016d). Consistent with the results of this thesis, research has also identified deleterious effects of avoidant coping on diverse aspects of health among patients with cancer (Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992; Hoyt et al., 2009; McCaul et al., 1999) and their caregivers (Kershaw et al., 2004). Collectively, these findings suggest that HNC patients and caregivers who perceive many consequences, a strong illness identity, and low control, and those who use avoidant strategies to cope, are at risk of poorer adjustment to the disease. Identification of these individuals could easily and efficiently be achieved using measures such as the Brief-IPQ (Broadbent et al., 2006) and the Brief COPE (Carver, 1997), providing the opportunity to intervene in an effort to prevent long-term difficulties.

Second, this thesis demonstrates the importance of considering the illness perceptions of HNC caregivers. Caregiver perceptions moderated relationships between patient illness perceptions and different domains of patient HRQL, with discrepancy having a particularly negative impact. Discrepancies between patient and caregiver perceptions of timeline, personal control, and illness identity were the strongest predictors of decreased patient HRQL over time, suggesting that efforts should be made to increase the degree of alignment with respect to these illness perception dimensions. Differences in the illness perceptions of patients with HNC and their caregivers largely stemmed from greater negativity among caregivers. Consequently, an effective technique to increase similarity in dyadic perceptions may be to promote more positive perceptions among caregivers, which could be achieved by reducing their levels of stress, depression, and anxiety. However, methods for improving the psychological wellbeing of HNC caregivers are yet to be established (Howren et al., 2013).

Third, the qualitative results highlight a need to improve the support provided to patients with HNC and their caregivers, particularly communication of information regarding diagnosis and treatment. Regrettably, the time that consultants have to communicate information about HNC to patients is limited. In a survey investigating the information giving practices of 254 ear, nose, and throat

consultants in the United Kingdom, surgeons reported an average of 15 minutes available for discussion with each patient (Stafford, Lewin, Nash, & Hardman, 2001). Additionally, almost all respondents reported providing information about diagnosis and treatment options during the same brief consultation. The limited time available for consultants to provide information may explain why many patients and their caregivers feel that current standards of information provision are inadequate (Ziegler et al., 2004). Satisfaction with information may be enhanced by developing easily comprehensible written materials that complement the verbal advice given by health care professionals (Semple & McGowan, 2002), and which allow individuals greater control over the content and amount of information they are exposed to.

Fourth, the findings demonstrate that interventions to address illness perceptions and coping may be beneficial for patients with HNC. Illness perceptions and coping strategies were related to patient HRQL, as well as patient and caregiver psychological wellbeing, suggesting that these variables are appropriate targets for intervention. The results of the RCT indicated that self-regulatory interventions may have the largest and most enduring benefit for HNC patient social HRQL. Such a positive impact on this outcome has not been identified in previous RCTs testing psychoeducation and CBT. Given the difficulties associated with social functioning following HNC treatment (Babin et al., 2008), and the importance of this HRQL domain to patients (Ramirez et al., 2003), self-regulatory interventions could be offered to all patients following diagnosis. Nevertheless, targeting illness perceptions and coping among patients who are distressed may achieve further changes in health outcomes, including psychological wellbeing. Research suggests that this approach, which is recommended in clinical practice guidelines, produces larger and more readily detectable changes in distress (Feldstain, Tomei, Belanger, & Lebel, 2014), and is more cost-effective as a result (Dieng, Cust, Kasparian, Mann, & Morton, 2016).

Regardless of whether individuals are screened for distress, the results of this thesis demonstrate that it is feasible to provide psychological support following HNC diagnosis and during treatment. Incorporating a health psychologist into the HNC multidisciplinary team may be an effective way to accommodate patient support needs at all stages of the HNC trajectory, a sentiment that has been expressed by other researchers in the field (Howren et al., 2013; Humphris, 2008; Morton, 2012). Self-regulatory techniques, including addressing illness perceptions and coping, could be provided over several brief sessions with a psychologist, resulting in enhanced long-term adjustment to the disease. These techniques could also be applied among caregivers of patients with HNC, who have

reported a strong desire for psychological assistance (Nightingale et al., 2016b), and whose wellbeing is inextricably linked to the wellbeing of patients (Hodges et al., 2005).

Limitations and Future Directions

While the work presented in this thesis has made several important contributions to the literature, there are also a number of limitations to consider. These limitations differ between Study 1, an observational prospective study, and Study 2, a pilot RCT. The limitations associated with each study are discussed in turn below. Opportunities for future research resulting from each study are also described.

Study 1

One of the most significant limitations associated with Study 1 is that the observational design prevented conclusions regarding whether the predictors under investigation were causally related to the psychological outcomes of patients with HNC and their caregivers. It is plausible that not only do illness perceptions and coping influence psychological responding among patients with HNC, but also that psychological states shape the development of illness perceptions and coping. It is also important to consider whether a third unmeasured variable could explain the relationships observed. This is particularly relevant in the context of HNC, where a diverse range of medical, psychological, and social characteristics have the potential to contribute to patient and caregiver adjustment.

The selection of predictor variables is another potential limitation of Study 1. The focus was on the role of illness perceptions and coping, based on the applicability of the CSM to a broad range of other illness groups, and preliminary evidence for the explanatory power of these variables among patients with HNC. However, a number of other psychological predictors have been identified as potentially important contributors to patient experiences of diagnosis, treatment, and recovery, including body image (disfigurement), personality traits, fear of cancer recurrence, continued tobacco and alcohol use, and availability of social support (Howren et al., 2013). Assessing these predictors would have made it possible to determine the relative contribution of each, allowing for identification of those most strongly associated with HNC patient and caregiver psychological outcomes.

Another limitation of the predictors examined is potential overlap in the constructs of illness perceptions and coping (Dempster et al., 2015). There is some evidence to suggest that responses to

assessments of illness perceptions may be confounded by an individual's appraisal of their available coping resources (Dempster & McCorry, 2012; McCorry et al., 2013). It is also possible that there was a large proportion of shared variance between the predictors and outcomes examined. For example, strong relationships were observed between patient perceptions of the consequences of HNC and their HRQL scores, consistent with the broader literature (e.g. Broadbent et al., 2015). However, appraisals of HRQL are likely to overlap with the severity of the consequences perceived to result from the condition. Investigation of illness perceptions and coping as constructs was also limited by the measurements used. In both cases, the briefest questionnaires available were selected (the Brief-IPQ and the Brief COPE) in order to minimise the burden of participation for HNC patients and their caregivers. However, these are more prone to measurement error than questionnaires that include multiple items per scale.

Self-report measures were used to assess each of the psychological predictors and outcomes under investigation. Although these measures have demonstrated utility, they are also subject to various sources of inaccuracy (Paulhus & Vazire, 2007). One such source is the use of response sets, whereby participants respond to questionnaire items in a systematic manner that negatively affects the validity of the data collected (Paulhus, 2002). Common examples include socially desirable responding, acquiescent responding, and extreme responding. There is also significant variation among participants with respect to their understanding and interpretation of individual questions and rating scales, and this is most pertinent when measuring abstract concepts as was the case in this thesis (Austin, Gibson, Deary, McGregor, & Dent, 1998). Difficulties with understanding may have been most problematic for patients and caregivers attempting to complete 6 month follow-up questionnaires, who did not have a researcher immediately available to ask questions and clarify items. In fact, this may have contributed to the significant loss to follow-up that occurred in Study 1. However, the low response rate at 6 months was also attributable to patient mortality and illness. There is an inherent response bias towards patients with less advanced cancers who experience less physical consequences of treatment when attempting to examine HRQL among patients with HNC (Llewellyn et al., 2007b).

The results of Study 1 suggest several important avenues for future research. The study was the first to investigate relationships between illness perceptions, coping, and psychological outcomes among both patients and their caregivers over time. Given that these variables could explain variation in not only patient but also caregiver wellbeing, further longitudinal research is needed to replicate the

findings. This could help to elucidate profiles of illness perceptions and coping that confer the greatest risk for patients and caregivers, respectively. Additional studies that enable the investigation of dyadic processes in the context of HNC are also needed. Specifically, research is necessary to examine potential mediators of the detrimental impact of illness perception discrepancy on patient wellbeing, and to examine whether discrepancy is related to caregiver outcomes. Finally, the experience of PTSD is under-investigated among patients with HNC and their caregivers, as well as in the wider cancer context. Despite a number of studies identifying its prevalence, almost all have employed cross-sectional designs and included patients with early stage breast cancer (Kangas, Henry, & Bryant, 2002). Patients with HNC, who frequently present with advanced stage cancer, experience more physically intrusive and disfiguring treatments, and are often male, may be more likely to experience severe PTSD reactions. Therefore, further longitudinal studies are needed to document PTSD prevalence in this group, as well as the predictors of this outcome.

Study 2

Study 2 employed a randomised controlled design, which is recognised as the most effective way to examine whether an intervention has been effective at causing a change in a predefined outcome (McCarthy, 2011). Nevertheless, there were a number of limitations associated with this study that are frequently observed in studies endeavouring to test psychological interventions for patients with HNC. First, there was a low rate of participation which resulted in a small sample size and reduced statistical power to detect significant effects. As a consequence, it was not possible to examine effects of the intervention on caregiver psychological wellbeing, and it is difficult to determine whether the results observed for patients are generalisable.

Another important limitation of Study 2 is the absence of an active control group. Participants who were not assigned to the intervention group received standard care alone. Therefore, it is possible that the improvements observed among patients in the intervention group were due to non-specific factors, such as patient expectations or the therapeutic relationship, rather than changes in illness perceptions and coping. Previous studies have found that these non-specific effects can account for most, if not all, of the observed benefits that are attributed to psychological interventions (Baskin, Tierney, Minami, & Wampold, 2003). In addition, group allocation was not concealed from the individuals involved in conducting and delivering Study 2, including the psychologist responsible for delivering the intervention. This can result in differential treatment of participants in each group as well

as differential assessment of outcome variables, biasing estimates of intervention effectiveness (Karanicolas, Farrokhyar, & Bhandari, 2010). However, the chances of this were minimised by having participants complete all measures without researchers or psychologist present.

The findings of Study 2 suggest that further exploration of interventions targeting illness perceptions and coping in patients with HNC and their caregivers is warranted. Future studies may develop and deliver self-regulatory interventions of a longer duration that extend into the post-treatment phase. This could produce additional changes in illness perceptions, resulting in notable improvements in a broader range of outcomes, including psychological distress. The effectiveness of targeting self-regulatory interventions to HNC patients experiencing high levels of distress at diagnosis also needs to be examined to determine whether this approach has larger effects on HRQL and psychological wellbeing. Efforts to increase the participation of caregivers in psychological interventions are necessary, given that research is yet to identify techniques that can reduce the psychological distress evident among these individuals. One approach may be to offer and deliver such interventions to caregivers individually. Finally, future research examining self-regulatory interventions for patients with HNC and their caregivers should include an active control group so that non-specific effects may be accounted for. This would allow conclusions to be drawn regarding whether changes in illness perceptions and coping (the active components of the intervention) are responsible for any positive changes in psychological outcomes.

Conclusion

Patients with HNC are known to experience significant detriments in HRQL as a consequence of their diagnosis and treatment. Furthermore, both patients and their caregivers are highly susceptible to psychological distress, including depression, anxiety, and PTSD. Few studies have endeavoured to identify factors that contribute to variation in these outcomes, and limited research has explored the effectiveness of psychological interventions at improving HNC patient and caregiver wellbeing. This thesis sought to improve understanding in these areas by exploring cross-sectional and longitudinal relationships between illness perceptions, coping, and psychological outcomes among patients and their caregivers, and by investigating the utility of a brief self-regulatory intervention. The results established that illness perceptions and coping strategies at diagnosis are independent predictors of psychological wellbeing among patients with HNC and their caregivers. The similarity of patient and caregiver illness perceptions was also found to be important, with discrepancies between these

perceptions related to lower subsequent HRQL for patients. An intervention designed to address illness perceptions and coping strategies early after diagnosis in face-to-face sessions with a psychologist was effective at producing positive changes in patient social HRQL over time. Further research is necessary to examine whether targeting self-regulatory interventions to patients experiencing distress may result in additional psychological benefits, and to determine whether such interventions can improve caregiver wellbeing. Nevertheless, the findings documented in this thesis suggest that the opportunity to see a psychologist following diagnosis and during treatment would be appreciated by many individuals affected by HNC. This might effectively be achieved by incorporating a health psychologist into the HNC multidisciplinary team, who has the expertise to manage the unique needs of this under-investigated patient population.

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Appendices

Appendix 1. Study 1 Patient Information Sheet

Reference Number: 9007



Department of Psychological Medicine

14 November 2012

This form will be stored for a period of six years

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PATIENT PARTICIPANT INFORMATION SHEET

Project title: Patient and family coping with head and neck cancer

Researchers: Dr Elizabeth Broadbent, Amy Richardson, Sandra Cavell, and Randall Morton

Researcher introduction

Dr Elizabeth Broadbent, Senior Lecturer in Health Psychology, Department of Psychological Medicine, Faculty of Medical and Health Sciences
Amy Richardson (MSc student), Faculty of Medical and Health Sciences
Sandra Cavell (Health Psychologist, CMDHB)
Randall Morton (Surgical Oncologist, ADHB and CMDHB)

Project description and invitation

You are invited to participate in a research study that aims to investigate coping strategies used by patients with head and neck cancer as well as their family members or caregivers. You have been invited to participate in this research because you attended the Head and Neck Outpatient Clinic at Auckland Hospital for initial diagnosis, between (February) and (August). Participation in this research is completely voluntary (you do not have to take part). You may withdraw from the study at any time and do not have to answer any questions that make you feel uncomfortable. Withdrawal from this study will in no way affect your future health care.

Project procedures

If you decide to participate you are requested to complete several questionnaires which may take about half an hour. The researchers will get some information from your medical records about the type of cancer you had and the treatment you received. This is so we can see whether this information is related to psychological adjustment after treatment. You will also be mailed the same questionnaires 6 months later which can be returned in an enclosed self-addressed envelope. This is so we can see whether your responses on these questionnaires change over time.

The questionnaires include detailed questions about your feelings and thoughts concerning your illness, how you are coping with it, and the types of social support that you may be receiving. Also, several questions will ask about your access to psychological help, and whether or not you think this may be beneficial for yourself or your family member(s).

Benefits and risks

This study is not expected to benefit patients. We do not anticipate any risks from participating in this study. If questionnaires raise issues regarding psychological health you will be provided with the contact details of those who can provide psychological help, and we can inform your GP if you wish.

Data storage

All data (questionnaires) will be stored in electronic format by the researchers. Paper questionnaires and consent forms will be stored in a locked filing cabinet in an office at the University, and will be kept for a period of six years.

Confidentiality

All personal information will remain strictly confidential and no material that could personally identify you will be used in any report on this study. Participant names will only appear on the consent form, which will be coded with a participant identification number so that your identity is kept confidential on all questionnaires. The investigators will only have access to your medical notes in relation to information that is relevant to this study.

After completion of the study, all confidential data, including computer data files, will be kept for a minimum period of six years to allow for publication and re-analysis, after which time it will be securely and confidentially disposed of. Research publications and presentations from the study will not contain any information that could personally identify you.

General information

For Maori health support or to discuss any concerns or issues regarding this study, please contact Mata Forbes, RGON, Maori Health Services Co-Ordinator/Advisor, Level 5, GM Suite, Auckland City Hospital.

Phone: 307 4949 ext. 23939

Results

A summary of the results of this study will be sent to you if you wish. As it takes some time to analyse the results of studies, it may be more than a year after your participation that you receive this information.

We appreciate the time you have taken to read this invitation. If you have any questions please contact:

Amy Richardson

Health Psychology student, Department of Psychological Medicine

Email: aric077@aucklanduni.ac.nz

Alternative contacts:

Dr Liz Broadbent, Department of Psychological Medicine, The University of Auckland

Email: e.broadbent@auckland.ac.nz

Phone: (09) 3737599 ext. 86756

Associate Professor Sally Merry, Department of Psychological Medicine

Email: s.merry@auckland.ac.nz

For ethical concerns, contact:

The Chair of The University of Auckland Human Participants Ethics Committee,

Office of the Vice Chancellor, Research Office,

Alfred Nathan House, The University of Auckland.

Phone: (09) 3737599 ext. 87830

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS
COMMITTEE ON
20/12/2012 for (3) years, Reference Number 9007

Appendix 2. Study 1 Patient Consent Form

Reference Number: 9007



Department of Psychological Medicine

14 November 2012

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PATIENT CONSENT FORM THIS FORM WILL BE HELD FOR A PERIOD OF 6 YEARS

Project title: Patient and family coping with head and neck cancer

Names of researchers: Dr Elizabeth Broadbent, Amy Richardson (health psychology student), Randall Morton (CMDHB), and Sandra Cavell (CMDHB).

I have read and understood the Participant Information Sheet, have understood the nature of the research, and know why I have been selected. I have had an opportunity to ask questions and have had them answered to my satisfaction.

- I agree to take part in this research.
- I understand that as part of the study, I will complete several questionnaires about my demographics, mental health, thoughts about head and neck cancer, ways of coping, and my perceived social support, and that this will occur now and in six months time.
- I understand that the researchers of this study will have access to my medical records for information about my diagnosis and treatment.
- I understand that I can stop completing these questionnaires at any time, for any reason.
- I understand that participation will take about 30 minutes on each separate occasion.
- I understand that if my questionnaire data suggests presence of mental distress, I will be provided with contact details for those who can provide psychological support.
- I understand that I am able to withdraw from the study at any time, and to withdraw any data traceable to me until I have finished the study.
- I wish / do not wish to receive a summary of the findings.
- I understand that the research data will be stored for 6 years after which they will be destroyed.
- I understand that the results of the study may be published but will not include any information that could identify me.

Name

Signature.....Date.....

Contact telephone number:

Please provide a mailing address.....

Appendix 3. Study 1 Caregiver Information Sheet

Reference Number: 9007



Department of Psychological Medicine

14 November 2012

This form will be stored for a period of six years

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extn 86756
Amy Richardson
Email: aric077@aucklanduni.ac.nz

FAMILY MEMBER PARTICIPANT INFORMATION SHEET

Project title: Patient and family coping with head and neck cancer

Researchers: Dr Elizabeth Broadbent, Amy Richardson, Sandra Cavell, and Randall Morton.

Researcher introduction

Dr Elizabeth Broadbent, Senior Lecturer in Health Psychology, Department of Psychological Medicine, Faculty of Medical and Health Sciences.

Amy Richardson (MSc student), Faculty of Medical and Health Sciences.

Sandra Cavell (Health Psychologist, CMDHB)

Randall Morton (Surgical Oncologist, ADHB and CMDHB)

Project description and invitation

You are invited to participate in a research study that aims to investigate coping strategies used by family members or caregivers of patients with head and neck cancer.

You have been invited to participate in this research because your family member attended the Head and Neck Outpatient Clinic at Auckland Hospital for initial diagnosis, between (February) and (August). Participation in this research is completely voluntary (you do not have to take part). You may withdraw from the study at any time and do not have to answer any questions that make you feel uncomfortable.

Project procedures

If you decide to participate you are requested to complete several questionnaires which may take about half an hour. This is so we can see whether this information is related to psychological adjustment after treatment. You will also be mailed the same questionnaires 6 months later which can be returned in an enclosed self-addressed envelope. This is so we can see whether your responses on these questionnaires change over time.

The questionnaires include detailed questions about your feelings and thoughts concerning your family member's illness, how you are coping with it, and the types of social support that you may be receiving. Also, several questions will ask about your access to psychological help, and whether or not you think this may be beneficial for yourself or your family member.

Benefits and risks

This study is not expected to be benefit family members of patients with head and neck cancer. We do not anticipate any risks from participating in this study. If questionnaires raise

issues regarding psychological health you will be provided with the contact details of those who can provide psychological help, and we can inform your GP if you wish.

Data storage

All data (questionnaires) will be stored in electronic format by the researcher. Paper questionnaires and consent forms will be stored in a locked filing cabinet in the researcher's office at the University.

Confidentiality

All personal information will remain strictly confidential and no material that could personally identify you will be used in any report on this study. Participant names will only appear on the consent form, which will be coded with a participant identification number so that your identity is kept confidential on all questionnaires.

After completion of the study, all confidential data, including computer data files, will be kept for a minimum period of six years to allow for publication and re-analysis, after which time it will be securely and confidentially disposed of. Research publications and presentations from the study will not contain any information that could personally identify you.

General information

For Maori health support or to discuss any concerns or issues regarding this study, please contact Mata Forbes, RGON, Maori Health Services Co-Ordinator/Advisor, Level 5, GM Suite, Auckland City Hospital.
Phone: 307 4949 ext. 23939

Results

A summary of the results of this study will be sent to you if you wish. As it takes some time to analyse the results of studies, it may be more than a year after your participation that you receive this information.

We appreciate the time you have taken to read this invitation. If you have any questions please contact:

Amy Richardson

Health Psychology student, Department of Psychological Medicine, The University of Auckland

Email: aric077@aucklanduni.ac.nz

Alternative contact:

Dr Liz Broadbent, Department of Psychological Medicine, The University of Auckland

Email: e.broadbent@auckland.ac.nz

Phone: (09) 3737599 ext. 86756

Associate Professor Sally Merry, Department of Psychological Medicine, The University of Auckland

Email: s.merry@auckland.ac.nz

For ethical concerns, contact:

The Chair of The University of Auckland Human Participants Ethics Committee,

Office of the Vice Chancellor, Research Office,

Alfred Nathan House, The University of Auckland,

Private Bag 92019, Auckland 1142.

Phone: (09) 3737599 ext. 87830

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS
COMMITTEE ON
20/12/2012 for (3) years, Reference Number 9007

Appendix 4. Study 1 Caregiver Consent Form

Reference Number: 9007



Department of Psychological Medicine

14 November 2012

The University of Auckland
Private Bag 92019
Auckland
New Zealand,

85 Park Road, Grafton
www.health.auckland.ac.nz

Elizabeth Broadbent
e.broadbent@auckland.ac.nz
Telephone: 64 9 373 7599
extn 86756
Amy Richardson
Email: aric077@aucklanduni.ac.nz

FAMILY MEMBER CONSENT FORM THIS FORM WILL BE HELD FOR A PERIOD OF 6 YEARS

Project title: Patient and family coping with head and neck cancer

Names of researchers: Dr Elizabeth Broadbent, Amy Richardson (health psychology student), Randall Morton (CMDHB), and Sandra Cavell (CMDHB).

I have read and understood the Participant Information Sheet, have understood the nature of the research, and know why I have been selected. I have had an opportunity to ask questions and have had them answered to my satisfaction.

- I agree to take part in this research.
- I understand that as part of the study, I will complete several questionnaires about my demographics, mental health, thoughts about head and neck cancer, ways of coping, and my perceived social support, and that this will occur now and in 6 months time.
- I understand that I can stop completing these questionnaires at any time, for any reason.
- I understand that participation will take about 30 minutes on each separate occasion.
- I understand that if my questionnaire data suggests presence of mental distress, I will be provided with contact details for those who can provide psychological support.
- I understand that I am able to withdraw from the study at any time, and to withdraw any data traceable to me until I have finished the study.
- I wish / do not wish to receive a summary of the findings.
- I understand that the research data will be stored for 6 years after which they will be destroyed.
- I understand that the results of the study may be published but will not include any information that could identify me.

Name

Signature.....Date.....

Contact telephone number:

Please provide a mailing address.....

Please provide an email address if you wish to receive a summary of the research findings.
.....

MAINTAINING YOUR RESEARCH APPROVAL

Your Ethical and Institutional approval is dependant on the Research Office having up-to-date information and documentation relating to your research and being kept informed of any changes to your study. While the RO endeavours to send reminders for annual approvals and missing documents, it is **your responsibility** to ensure you have kept Ethics and the Research office up to date and have the appropriate approvals.

Please note, when missing or updated document reminders are sent, if the RO receives no response from you after **3 reminders** it will be assumed that your research has been completed and we will notify the relevant Department CD, the RRC and Ethics Committee that your **Locality Assessment Approval has been withdrawn**. This will not be reinstated until all issues have been resolved.

All documents / communications must be referenced with the **ADHB project number**. For simplicity when sending information to the Ethics Committees, please cc the RO. When receiving letters from Ethics, please copy and send to RO for our records.

TOPIC	REQUIREMENT	ACTION
ETHICS		
All Ethics Correspondence	All formal Ethics Committee communications to you	<ul style="list-style-type: none"> ○ send a copy to RO immediately
Annual Ethics Renewal	Use Ethics form, complete and submit BEFORE anniversary date of original research approval	<ul style="list-style-type: none"> ○ copy to Ethics ○ copy to RO (e-copy) ○ send copy of Ethics approval letter to RO when received
Changes to Research (design, PI, protocol etc)	Write letter detailing changes, Mark up changes in relevant documents. Ethics approval must be received BEFORE implementing	<ul style="list-style-type: none"> ○ copy of changes to Ethics ○ copy changes to RO ○ send copy of Ethics approval letter to RO when received
Stopping Study or Study Complete	If the study is stopped for any reason or study is complete	<ul style="list-style-type: none"> ○ notify Ethics and attach relevant documents (final report etc) ○ notify RO and attach relevant documents
Final Report	Complete Ethics template for final report	<ul style="list-style-type: none"> ○ Send to Ethics and RO ○ Inform RO if all finance elements also complete
LEGAL		
Contracts, Indemnities, Agreements, insurance certificates	All legal must be reviewed and approved before signing	<ul style="list-style-type: none"> ○ Send all legal documents to RO
Amendments – Non-financial	As above	<ul style="list-style-type: none"> ○ Send all legal documents to RO
Amendments - financial	As above and revise Budget	<ul style="list-style-type: none"> ○ Send all legal documents to RO ○ Send revised budget using template to RO
FINANCIAL		
Budget Changes i.e. change in visits or tests or proposed income	Liaise with accountant and adjust budget accordingly	<ul style="list-style-type: none"> ○ Send revised budget using template to RO
Budget maintenance	it is recommended that you review and update budgets at least quarterly	<ul style="list-style-type: none"> ○ Liaise with accountant and forward update to RO

All documents must be referenced with the ADHB project number and can be sent via email to: RDOAdmin@adhb.govt.nz. All paper copies can be faxed to: 09 307 8913 or by post to: Research Office, Level 14, Support Building, Auckland City Hospital, Private Bag 92024, Auckland, New Zealand.

For further information go to www.adhb.govt.nz/researchoffice/



Appendix 6. Study 2 Patient Information Sheet



Participant Information Sheet

Patient

Study title: **A Self-Regulation Intervention to Improve Psychological Wellbeing in Patients with Head and Neck Cancer and Their Caregivers**

Locality: **ADHB**

Ethics committee ref:

14/NTB/15

Lead investigator: **Elizabeth Broadbent (PhD)**

Contact phone number:

64 9 373 7599 ext. 86756

You are invited to take part in a study investigating whether a psychological intervention providing information and coping strategies for head and neck cancer can improve your mental health and quality of life.

Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. We will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to find out whether a self-regulation intervention (that is, an intervention to change the way you think about your illness and improve the way you cope), can improve quality of life and reduce psychological distress after treatment for head and neck cancer.

A Self-Regulation Intervention to Improve Psychological Wellbeing in Patients with Head and Neck Cancer and Their Caregivers y study title:

PIS/CF version no.:

Dated:31/01/2014

Page 1 of 6

If you choose to participate in the study, you will be randomly assigned to receive the intervention in addition to standard care, or to receive standard care alone. This is done so that we can compare the benefits of the intervention with current best practice. Randomisation also prevents any bias that may arise if the investigators are able to influence who takes part in the intervention and who does not.

This study has been approved by the New Zealand Health and Disability Ethics Committee on the 04/04/2014.

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

You have been invited to participate in the study because you were diagnosed with head and neck cancer or skin cancer on the head or neck at some point within the past four weeks.

If you agree to participate in the study, you may be assigned to take part in a self-regulatory intervention designed to improve quality of life and psychological wellbeing following treatment for head and neck cancer. Alternatively, you may be assigned to receive standard care alone. This means that you will have the same care that you would have had if you were not participating in the study.

As part of the study, you will complete questionnaires that are designed to assess illness perceptions, coping, depression, anxiety, post-traumatic stress, quality of life, and fear of recurrence. These will be completed before you are randomised to the intervention or the standard care group, 3 months later, and again at 6 months. It is anticipated that these questionnaires will take approximately 30 minutes to complete each time.

If you are randomly assigned to receive the intervention, you will participate in three 45 minute sessions (involving just you, and a family member if desired) that are designed to: inform you about your treatment, and give you some useful strategies for coping with your illness. Intervention sessions will be conducted by a health psychologist and will take place at Auckland Hospital or at your home if this is preferred. A 30 minute follow-up phone call will also take place one month after the intervention sessions have been completed.

Health information will be collected from you indirectly by accessing your medical records. The investigators will collect information on the type of cancer that you have, and how this is treated.

WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?

There are no foreseeable risks, side-effects and discomforts of participating in this study for either you or your family members.

There are some possible benefits of participating in this study if you are assigned to the intervention group. It is anticipated that the intervention will improve the way that you cope

with your head and neck cancer diagnosis and treatment, and improve your mental health and quality of life as a result.

WHO PAYS FOR THE STUDY?

This study has been funded by research grants from the Oakley Mental Health Research Foundation and the Maurice and Phyllis Paykel Trust to pay the salary of a health psychologist, who will be responsible for delivering the intervention.

As a small token of appreciation you will receive a \$50 Westfield gift voucher once all parts of the study have been completed. You will not incur any costs if you decide to participate in the study.

WHAT IF SOMETHING GOES WRONG?

If you were injured in this study, which is unlikely, you would be eligible for compensation from ACC just as you would be if you were injured in an accident at work or at home. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will receive funding to assist in your recovery.

WHAT ARE MY RIGHTS?

Participation in this study is entirely voluntary, meaning that you are free to decline to participate, or to withdraw from the research at any time, without experiencing any disadvantage.

You have the right to access any information that is collected about you as part of this study.

All personal information belonging to you will be kept strictly confidential and no material that could personally identify you will be used in any report on this study. Your name will only appear on your consent form, which will be coded with a participant identification number so that your identity is kept confidential on all questionnaires.

Only medical notes that are relevant to this study will be used.

After completion of the study, all confidential data, including computer data files, will be kept for a minimum period of six years to allow for publication and re-analysis, after which time it will be securely and confidentially disposed of.

WHAT HAPPENS AFTER THE STUDY?

All data (questionnaires) will be stored in electronic format by the investigators. Paper questionnaires and consent forms will be stored in a locked filing cabinet at the University of Auckland, and will be kept for a period of six years.

A summary of the results of this study will be sent to you if you wish. As it takes some time to analyse the results of studies, it may be more than a year after your participation before you receive this information.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

The investigators are:

Dr. Elizabeth Broadbent, Senior Lecturer, Dept. of Psychological Medicine, The University of Auckland.

Amy Richardson, PhD Candidate, Dept. of Psychological Medicine, The University of Auckland.

Professor Randall Morton, Consultant Otolaryngologist-Head & Neck Surgeon (CMDHB), Professor of Otolaryngology, The University of Auckland, Clinical Director of the Manukau Surgery Centre (CMDHB)

The best person to contact if you have any questions about the study is Amy Richardson. You can contact her on phone: 09 373 7599 ext 89473, or by email: aric077@aucklanduni.ac.nz

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Elizabeth Broadbent, Senior Lecturer
Telephone: 64 9 373 7599
Email: e.broadbent@auckland.ac.nz

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@hdc.org.nz

For Maori health support please contact :

Mata Forbes, RGON, Maori Health Services Coordinator/Advisor
Level 5, GM Suite, Auckland City Hospital
Telephone number: 64 9 307 4949 ext. 23939

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS
Email: hdecs@moh.govt.nz

Appendix 7. Study 2 Patient Consent Form

Consent Form

Patient

If you need an INTERPRETER, please tell us.

Please tick to indicate you consent to the following

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I have been given sufficient time to consider whether or not to participate in this study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I have had the opportunity to use a legal representative, whanau/ family support or a friend to help me ask questions and understand the study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I consent to the research staff collecting and processing my information, including information about my health.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I consent to my GP or current provider being informed about my participation in the study and of any significant abnormal results obtained during the study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I agree to an approved auditor appointed by the New Zealand Health and Disability Ethic Committees, or any relevant regulatory authority or their approved representative reviewing my relevant medical records for the sole purpose of checking the accuracy of the information recorded for the study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>

A Self-Regulation Intervention to Improve Psychological Wellbeing in Patients with Head and Neck Cancer and Their Caregivers y study title:

PIS/CF version no.:

Dated:31/01/2014

Page 5 of 6

I understand the compensation provisions in case of injury during the study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I know who to contact if I have any questions about the study in general.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand my responsibilities as a study participant.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I wish to receive a summary of the results from the study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Declaration by participant:

I hereby consent to take part in this study.

Participant's name: _____

Signature: _____ Date: _____

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: _____

Signature: _____ Date: _____

MAINTAINING YOUR RESEARCH APPROVAL

Your Ethical and Institutional approval is dependant on the Research Office having up-to-date information and documentation relating to your research and being kept informed of any changes to your study. While the RO endeavours to send reminders for annual approvals and missing documents, it is **your responsibility** to ensure you have kept Ethics and the Research office up to date and have the appropriate approvals.

Please note, when missing or updated document reminders are sent, if the RO receives no response from you after **3 reminders** it will be assumed that your research has been completed and we will notify the relevant Department CD, the RRC and Ethics Committee that your **Locality Assessment Approval has been withdrawn**. This will not be reinstated until all issues have been resolved.

All documents / communications must be referenced with the **ADHB project number**. For simplicity when sending information to the Ethics Committees, please cc the RO. When receiving letters from Ethics, please copy and send to RO for our records.

TOPIC	REQUIREMENT	ACTION
ETHICS		
All Ethics Correspondence	All formal Ethics Committee communications to you	<ul style="list-style-type: none"> o send a copy to RO immediately
Annual Ethics Renewal	Use Ethics form, complete and submit BEFORE anniversary date of original research approval	<ul style="list-style-type: none"> o copy to Ethics o copy to RO (e-copy) o send copy of Ethics approval letter to RO when received
Changes to Research (design, PI, protocol etc)	Write letter detailing changes, Mark up changes in relevant documents. Ethics approval must be received BEFORE implementing	<ul style="list-style-type: none"> o copy of changes to Ethics o copy changes to RO o send copy of Ethics approval letter to RO when received
Stopping Study or Study Complete	If the study is stopped for any reason or study is complete	<ul style="list-style-type: none"> o notify Ethics and attach relevant documents (final report etc) o notify RO and attach relevant documents
Final Report	Complete Ethics template for final report	<ul style="list-style-type: none"> o Send to Ethics and RO o Inform RO if all finance elements also complete
LEGAL		
Contracts, Indemnities, Agreements, insurance certificates	All legal must be reviewed and approved before signing	<ul style="list-style-type: none"> o Send all legal documents to RO
Amendments – Non-financial	As above	<ul style="list-style-type: none"> o Send all legal documents to RO
Amendments - financial	As above and revise Budget	<ul style="list-style-type: none"> o Send all legal documents to RO o Send revised budget using template to RO
FINANCIAL		
Budget Changes i.e. change in visits or tests or proposed income	Liaise with accountant and adjust budget accordingly	<ul style="list-style-type: none"> o Send revised budget using template to RO
Budget maintenance	it is recommended that you review and update budgets at least quarterly	<ul style="list-style-type: none"> o Liaise with accountant and forward update to RO

All documents must be referenced with the ADHB project number and can be sent via email to: jennym@adhb.govt.nz. All paper copies can be faxed to, Attention: Jenny Ma, internal # 23789, external # 09 630 9978 or sent by post, Attention: Jenny Ma, Research Office, Level 14, Support Building, Auckland City Hospital, Private Bag 92024, Auckland, New Zealand.

For further information go to www.adhb.govt.nz/researchoffice/

04 April 2014

Miss Amy Richardson
85 Park Road
Grafton
The University of Auckland
Private Bag 92019
Auckland 0630

Dear Miss Richardson

Re: Ethics ref:	14/NTB/15
Study title:	Effects of a Self-Regulation Intervention on Coping, Quality of Life, and Psychological Wellbeing in Patients with Head and Neck Cancer and Their Caregivers: A Randomized Controlled Trial

I am pleased to advise that this application has been approved by the Northern B Health and Disability Ethics Committee. This decision was made through the HDEC-Expedited Review pathway.

Thank you for clarification around the consent process. The practicalities of obtaining consent within a limited time window are noted. However, the committee feel strongly that in accordance with the National Ethics Advisory Committee (NEAC) guidelines on obtaining free and valid informed consent (with reference also to vulnerable populations) that the emphasis on the consent process is to ensure patients are **given adequate time to consider participation and are able to provide valid consent when not overwhelmed or in a stressful situation.**

Approval is therefore given on the basis that in accordance with section 6.18, NEAC guidelines that during the initial consent discussion (at outpatient clinic in this instance), due regard should be paid to the circumstances of the potential participant. Therefore only a short discussion/introduction of the study should be made at the time of the outpatient visit and only if the Investigator believes the patient is not overwhelmed with information at this time or in a stressful situation that would create difficulties in understanding.

Consent should not be obtained at this time but rather an initial brief discussion (where the Investigator feels that a brief introduction at the time of outpatient visit is appropriate) should be followed up with more detailed information at a later time, removed from the diagnosis/treatment outpatient visit.

The responsibility for obtaining free and valid consent remains with the Investigator and the comments above are to ensure that **sufficient time is afforded to all participants in making informed consent decisions.**

Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Northern B Health and Disability Ethics Committee is required.

Appendix A
Documents submitted

<i>Document</i>	<i>Version</i>	<i>Date</i>
CV for CI	1	03 February 2014
CVs for other Investigators	1	03 February 2014
Protocol	1	03 February 2014
Survey/questionnaire	1	03 February 2014
Survey/questionnaire: 3 month follow-up questionnaire - patients	1	03 February 2014
Survey/questionnaire: 6 month follow-up questionnaire - patients	1	03 February 2014
PIS/CF: PIS/CF - patient	1	03 February 2014
Survey/questionnaire	1	03 February 2014
Survey/questionnaire: 3-month follow-up questionnaire - caregivers	1	03 February 2014
Survey/questionnaire: 6 month follow-up questionnaire - caregivers	1	03 February 2014
Evidence of scientific review	1	04 February 2014
Application		04 February 2014
Evidence of scientific review		07 February 2014
HDEC_Response to Further Information request.docx		05 March 2014

Appendix B
Statement of compliance and list of members

Statement of compliance

The Northern B Health and Disability Ethics Committee:

- is constituted in accordance with its Terms of Reference
- operates in accordance with the *Standard Operating Procedures for Health and Disability Ethics Committees*, and with the principles of international good clinical practice (GCP)
- is approved by the Health Research Council of New Zealand's Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990
- is registered (number 00008715) with the US Department of Health and Human Services' Office for Human Research Protection (OHRP).

List of members

<i>Name</i>	<i>Category</i>	<i>Appointed</i>	<i>Term Expires</i>
Mrs Raewyn Sporle	Lay (the law)	01/07/2012	01/07/2015
Mrs Maliaga Erick	Lay (consumer/community perspectives)	01/07/2012	01/07/2014
Mrs Kate O'Connor	Non-lay (other)	01/07/2012	01/07/2015
Mrs Stephanie Pollard	Non-lay (intervention studies)	01/07/2012	01/07/2015
Dr Paul Tanser	Non-lay (health/disability service provision)	01/07/2012	01/07/2014
Ms Kerin Thompson	Non-lay (intervention studies)	01/07/2012	01/07/2015

<http://www.ethics.health.govt.nz>

Appendix 9. Study 2 Patient Questionnaire

CODE				
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DATE			
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THE UNIVERSITY OF AUCKLAND
FACULTY OF MEDICAL AND
HEALTH SCIENCES

QUESTIONNAIRES ASSESSING PSYCHOLOGICAL ADJUSTMENT TO HEAD AND NECK CANCER

Patient Baseline

The following questionnaires are designed to gather some background information on your current circumstances and your feelings about your illness. All of the information you provide us is in confidence and will be used only for the purposes of this study.

Many of these questions ask about your attitudes and beliefs about your illness. For these questions there are no right or wrong answers – an answer is correct if it is true for you.

We are most interested in your own opinion or view of things rather than that of your doctor or others you may have talked to. Please choose the response that best fits with your circumstances.

Do not linger over each question; normally the first response is best. If you have any queries about the questionnaire please contact the researchers, who will be happy to assist you.

Thank you for your participation in this study.



Background Information

Please answer the following questions by filling in the blanks or ticking the boxes that best correspond to you:

1. How old are you?	
2. Are you male or female?	Male <input type="checkbox"/> Female <input type="checkbox"/>
3. Which ethnic group do you belong to?	<p><i>Mark the space or spaces which apply to you.</i></p> <ul style="list-style-type: none"> <input type="checkbox"/> New Zealand European/Pakeha <input type="checkbox"/> Māori <input type="checkbox"/> Samoan <input type="checkbox"/> Cook Island Maori <input type="checkbox"/> Tongan <input type="checkbox"/> Niuean <input type="checkbox"/> Chinese <input type="checkbox"/> Indian <input type="checkbox"/> other such as <i>DUTCH, JAPANESE, TOKELAUAN</i>. Please state:

4. At what level did you complete your formal education? (Please tick the appropriate box)

Primary school	
Secondary school (up to 4 th Form)	
Secondary school (including 5 th Form)	
Secondary school (including 6 th or 7 th Form)	
Technical or Trade Certificate	
University or Polytechnic Diploma	
University degree	

5. What is your employment status?

Employed - full time	
Employed - part time	
Unemployed	
Retired	
Work at home	
Student	
Beneficiary	

6. What is your marital status?

Single (never married)	
Married/ de facto relationship	
Divorced or separated	
Widowed	

7. What are your current living arrangements?

Living with partner or spouse and children	
Living with partner or spouse and no children	
Sole adult with children	
Living alone	
Living with other adults (e.g. relatives, friends)	
Other (please specify)	

8. Are you a smoker?

_____ Yes _____ No

If yes, how often and how much would you smoke on average? (e.g. one packet a day; two cigarettes a week etc)

9. Do you drink alcohol?

_____ Yes _____ No

If yes, how often and how much would you drink on average? (e.g. a glass of wine a day; a dozen cans of beer a week)

10. During your average week, how many times and for how long (per session) do you engage in strenuous exercise?

11. How many hours sleep would you get on average per night? _____

Health-Related Quality of Life

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

<u>PHYSICAL WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
GP 1	I have a lack of energy	0	1	2	3	4
GP 2	I have nausea	0	1	2	3	4
GP 3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP 4	I have pain	0	1	2	3	4
GP 5	I am bothered by side effects of treatment	0	1	2	3	4
GP 6	I feel ill	0	1	2	3	4
GP 7	I am forced to spend time in bed	0	1	2	3	4

<u>SOCIAL/FAMILY WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
GS 1	I feel close to my friends	0	1	2	3	4
GS 2	I get emotional support from my family	0	1	2	3	4
GS 3	I get support from my friends	0	1	2	3	4

		Not at all	A little bit	Some-what	Quite a bit	Very much
GS 4	My family has accepted my illness	0	1	2	3	4
GS 5	I am satisfied with family communication about my illness	0	1	2	3	4
GS 6	I feel close to my partner (or the person who is my main support).....	0	1	2	3	4
Q1	<i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box <input type="checkbox"/> and go to the next section.</i>					
GS 7	I am satisfied with my sex life.....	0	1	2	3	4

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

		Not at all	A little bit	Some-what	Quite a bit	Very much
GE1	I feel sad.....	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness.....	0	1	2	3	4
GE3	I am losing hope in the fight against my illness.....	0	1	2	3	4
GE4	I feel nervous.....	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4

GE6	I worry that my condition will get worse.....	0	1	2	3	4
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FUNCTIONAL WELL-BEING

		Not at all	A little bit	Some-what	Quite a bit	Very much
GF1	I am able to work (include work at home).....	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life.....	0	1	2	3	4
GF4	I have accepted my illness.....	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

ADDITIONAL CONCERNS

		Not at all	A little bit	Some-what	Quite a bit	Very much
H&N1	I am able to eat the foods that I like	0	1	2	3	4
H&N2	My mouth is dry	0	1	2	3	4
H&N3	I have trouble breathing	0	1	2	3	4

		Not at all	A little bit	Some- what	Quite a bit	Very much
H&N4	My voice has its usual quality and strength.....	0	1	2	3	4
H&N5	I am able to eat as much food as I want.....	0	1	2	3	4
H&N6	I am unhappy with how my face and neck look.....	0	1	2	3	4
H&N7	I can swallow naturally and easily	0	1	2	3	4
H&N8	I smoke cigarettes or other tobacco products.....	0	1	2	3	4
H&N9	I drink alcohol (e.g. beer, wine, etc.)	0	1	2	3	4
H&N 10	I am able to communicate with others.....	0	1	2	3	4
H&N 11	I can eat solid foods.....	0	1	2	3	4
H&N 12	I have pain in my mouth, throat or neck	0	1	2	3	4

General Health Questionnaire – 12 Items

We want to know how your health has been in general over the last few weeks. Please read the questions below and each of the four possible answers. Tick the response that best applies to you.

1. Have you recently been able to concentrate on what you're doing?

Better than usual Same as usual Less than usual Much less than usual

2. Have you recently lost much sleep over worry?

Not at all No more than usual Rather more than usual Much more than usual

3. Have you recently felt that you are playing a useful part in things?

More so than usual Same as usual Less useful than usual Much less useful than usual

4. Have you recently felt capable of making decisions about things?

More so than usual Same as usual Less so than usual Much less than usual

5. Have you recently felt constantly under strain?

Not at all No more than usual Rather more than usual Much more than usual

6. Have you recently felt you couldn't overcome your difficulties?

Not at all No more than usual Rather more than usual Much more than usual

7. Have you recently been able to enjoy your normal day-to-day activities?

More so than usual Same as usual Less so than usual Much less than usual

8. Have you recently been able to face up to your problems?

More so than usual Same as usual Less so than usual Much less than usual

9. Have you recently been feeling unhappy or depressed?

Not at all No more than usual Rather more than usual Much more than usual

10. Have you recently been losing confidence in yourself?

Not at all No more than usual Rather more than usual Much more than usual

11. Have you recently been thinking of yourself as a worthless person?

Not at all No more than usual Rather more than usual Much more than usual

12. Have you recently been feeling reasonably happy, all things considered?

More so than usual Same as usual Less so than usual Much less than usual

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YOUR FEELINGS AND EMOTIONS

Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Not being able to stop or control worrying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Worrying too much about different things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Trouble relaxing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Being so restless that it is hard to sit still	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Becoming easily annoyed or irritable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Feeling afraid as if something awful might happen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you were bothered by any of these problems, how difficult have these problems made it for you to do your work, take care of things at work, or get along with other people?

Not difficult at all Somewhat difficult Very difficult Extremely difficult

Brief Illness Perception Questionnaire

We are interested in your perceptions of your head and neck cancer. For each of the questions below, please circle the number that best corresponds to your views:

<p>How much does your head and neck cancer affect your life?</p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p>No effect at all Severely affects my life</p>
<p>How long do you think your head and neck cancer will continue?</p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p>A very short time Forever</p>
<p>How much control do you feel you have over your head and neck cancer?</p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p>Absolutely no control Extreme amount of control</p>
<p>How much do you think your treatment can help your head and neck cancer?</p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p>Not at all Extremely helpful</p>
<p>How much do you experience symptoms from your head and neck cancer?</p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p>No symptoms at all Many severe symptoms</p>
<p>How concerned are you about your head and neck cancer?</p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p>Not at all concerned Extremely concerned</p>
<p>How well do you feel you understand your head and neck cancer?</p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p>Not at all A great deal</p>
<p>How much does your head and neck cancer affect you emotionally? (e.g. does it make you angry, scared, anxious or depressed?)</p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p>Not at all affected emotionally Extremely affected emotionally</p>

Brief Cope Questionnaire

These items deal with ways you've been coping with the stress in your life since you found out about your illness. There are many ways to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but we are interested in how you've tried to deal with this problem. We want to know to what extent you've been doing what the item says - how much or how frequently.

Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
I've been turning to work or other activities to take my mind off things.				
I've been concentrating my efforts on doing something about the situation I'm in.				
I've been saying to myself "this isn't real".				
I've been using alcohol or other drugs to make myself feel better.				
I've been getting emotional support from others.				
I've been giving up trying to deal with it.				
I've been taking action to try to make the situation better.				
I've been refusing to believe that it has happened.				
I've been saying things to let my unpleasant feelings escape.				
I've been getting help and advice from other people.				
I've been using alcohol or other drugs to help me get through it.				
I've been trying to see it in a different light, to make it seem more positive.				
I've been criticizing myself.				
I've been trying to come up with a strategy about what to do.				

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
I've been getting comfort and understanding from someone.				
I've been giving up the attempt to cope.				
I've been looking for something good in what is happening.				
I've been making jokes about it.				
I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.				
I've been accepting the reality of the fact that it has happened.				
I've been expressing my negative feelings.				
I've been trying to find comfort in my religion or spiritual beliefs.				
I've been trying to get advice or help from other people about what to do.				
I've been learning to live with it.				
I've been thinking hard about what steps to take.				
I've been blaming myself for things that happened.				
I've been praying or meditating.				
I've been making fun of the situation.				

PTSD Symptom Scale (PSS)

Below is a list of problems that people sometimes have after stressful events (such as being diagnosed with or treated for cancer). Please rate on a scale from 0-3 how much or how often these following things have occurred to you in the last two weeks:

- 0 Not at all**
1 Once per week or less/ a little bit/ one in a while
2 2 to 4 times per week/ somewhat/ half the time
3 3 to 5 or more times per week/ very much/ almost always

1. Having upsetting thought or images about the stressful event that come into your head when you did not want them to	0	1	2	3
2. Having bad dreams or nightmares about the stressful event	0	1	2	3
3. Reliving the stressful event (acting as if it were happening again)	0	1	2	3
4. Feeling emotionally upset when you are reminded of the stressful event	0	1	2	3
5. Experiencing physical reactions when reminded of the stressful event (sweating, increased heart rate)	0	1	2	3
6. Trying not to think or talk about the stressful event	0	1	2	3
7. Trying to avoid activities or people that remind you of the stressful event	0	1	2	3
8. Not being able to remember an important part of the stressful event	0	1	2	3
9. Having much less interest or participating much less often in important activities	0	1	2	3
10. Feeling distant or cut off from the people around you	0	1	2	3
11. Feeling emotionally numb (unable to cry or have loving feelings)	0	1	2	3
12. Feeling as if your future hopes or plans will not come true	0	1	2	3
13. Having trouble falling or staying asleep	0	1	2	3
14. Feeling irritable or having fits of anger	0	1	2	3
15. Having trouble concentrating	0	1	2	3
16. Being overly alert	0	1	2	3
17. Being jumpy or easily startled	0	1	2	3

Please mark YES or NO if the problems above interfered with the following:

- | | | | |
|---------------------------|--|------------------------------|--|
| 1. Work | <input type="checkbox"/> Yes <input type="checkbox"/> No | 6. Family relationships | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 2. Household duties | <input type="checkbox"/> Yes <input type="checkbox"/> No | 7. Sex life | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 3. Friendships | <input type="checkbox"/> Yes <input type="checkbox"/> No | 8. General life satisfaction | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 4. Fun/leisure activities | <input type="checkbox"/> Yes <input type="checkbox"/> No | 9. Overall functioning | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 5. Schoolwork | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |