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List of abbreviations

AIDS	Acquired Immune-deficiency Syndrome
ART	Antiretroviral Therapy
CBOs	Community Based Organisations
CCHBC	Comprehensive Community Home Based Care
C&HBC	Community and Home Based Care
CHW	Community Health Workers
CSPRO	Census and Survey Processing System
NCDs	Non-Communicable Diseases
CSDH	Commission on Social Determinants of Health
DACs	District AIDS Coordinators
DSD	Department of Social Development
FACT Rusape	Family AIDS Caring Trust Rusape
FBO	Faith Based Organisation
FGD	Focus Group Discussion
GoZ	Government of Zimbabwe
HBC	Home Based Care
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
HRQoL	Health Related Quality of Life
ICF	International Coach Federation
ICTs	Information Community Technologies
IEC	Information, Education and Communication
IGA	Income Generating Activity
KI	Key Informant
KIIs	Key Informants Interviews
IT	Information Technology
MoESC	Ministry of Education, Sport and Culture
MoF	Ministry of Finance
MoHCW	Ministry of Health and Child Welfare
MoLSS	Ministry of Public Service, Labour and Social Services
MoMIP	Ministry of Information Media, Information and Publicity
MRCZ	Medical Research of Zimbabwe
MTR	Mid-Term Review
NAC	National AIDS Council

List of abbreviations

NCDs	Non-Communicable Diseases
NGOs	Non-Governmental Organisations
NAC	National Aids Council
OI/ART	Opportunistic Infection/Antiretroviral therapy
OIs	Opportunistic Infections
OVC	Orphans and Vulnerable Children
PLH	People Living with HIV
QoL	Quality of Life
RHCs	Rural Health Centres
SPSS	Statistical Package for Social Sciences
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV and AIDS
UNICEF	United Nations Children's Fund
UNISA	University of South Africa
USD	United States Dollars
WFP	World Food Programme
WHO	World Health Organization
ZAN	Zimbabwe AIDS Network
ZDHS	Zimbabwe Development Health Survey
ZIMSTAT	Zimbabwe National Statistics Agency
ZNASP	Zimbabwe National HIV and AIDS Strategic Plan

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CHAPTER 1

ORIENTATION OF THE STUDY

1.1 INTRODUCTION AND BACKGROUND

The past two decades have witnessed transition from in-patient hospital admission and care to community and home based care, due to the upsurge in chronic health conditions. This has been caused by the heightening of the Human Immunodeficiency Virus (HIV) and Acquired Immune-deficiency Syndrome (AIDS) epidemic, particularly in Sub-Sahara Africa, and in Zimbabwe (which has one of the highest HIV prevalence rates in the world).

There is also a growing belief in allowing patients to interact as partners in the care process and contributing at every stage of their care plan. If patient's input and goals for good health and care are key to successful health outcomes, it is important that this study examines factors that influence implementation of community and home based care initiatives.

1.1.1 The health system in Zimbabwe

The World Health Organization (WHO) defines a health system as “all the activities whose primary purpose is to promote, restore or maintain health” (WHO 2000a:5). Zimbabwe's health services are divided into four levels of care: primary, secondary, tertiary, and quaternary. Primary level of care includes rural health centres (RHCs) and community based health services. There are also government, private sector, mission and municipal clinics at this level. The district hospitals fall within the secondary level of care. The tertiary level consists of provincial hospitals, and at quaternary level, are central hospitals. The system is organised in such a way that rural health centres refer patients to district hospitals, which in turn refer them to provincial hospitals. The provincial hospitals then refer patients to central hospitals. However, there are situations where referrals do not follow this pattern, due either to the close proximity or the distant location of the large health institutions, and also due to lack of qualified health

professionals. The other reason for the break in the referral pattern may be due to the non-availability of advanced equipment at many institutions that are lower than the tertiary level. In addition to municipality and government health facilities, there are private clinics and hospitals catering for the middle and upper class members of society. Large corporate companies operate their own clinics and hospitals, mainly offering services to company employees and their dependents. Community based health services compliment services offered in all levels of health care.

The Zimbabwe health system is recovering from a decade of economic decline, which has adversely affected health service delivery and has reduced post-independence developments. (Osika, Altman, Ekblad, Katz, Nguyen, Rosenfeld, Williamson & Tapera 2010:28). This period was characterised by hyperinflation and a shortage of supplies, including health-related equipment and medicines. The health sector has developed and adopted several policies, strategic plans and guidelines to ensure standardised care and treatment, as well as to guide implementation of health service delivery by the public and private sectors. Two policy documents that are relevant to this study are described below. Other important policies and guidelines will be referred to in relevant sections of this study.

1.1.1.1 National Health Strategy: 2009-2013

The Zimbabwe National Health Strategy is a planning and implementation guide for all stakeholders (government and non-governmental) involved in health activities in the country. It focuses on promoting and improving the quality of services and ensuring equity in the delivery of these services. The strategy is based on four thematic areas which are as follows (Zimbabwe MoHCW & NAC 2009a:31):

- **Determinants of Health** – addressing the factors outside the health sector which impact on health.
- **Diseases affecting Zimbabweans** – addressing the burden of specific diseases and conditions affecting Zimbabweans.
- **Health System Strengthening** – supporting the overall health system context in which services must be planned, delivered and monitored.
- **Inclusive Implementation** – acknowledging and enabling the actions of a wide range of stakeholders.

The strategy also recognises that “community participation enhances quality health care, and ideas for the health system can be influenced by the service users” (Zimbabwe MoHCW & NAC 2009a:11). It also underscores the importance of a broader focus in developing and implementing successful health services, as it states that “good health and quality of life do not derive only from the health sector, but are influenced by a myriad of other factors which are outside its direct influence. All sectors of the economy impact on the health and quality of life of all citizens through their direct influence on the social determinants of health” (Zimbabwe MoHCW & NAC 2009a:22).

1.1.1.2 Zimbabwe National HIV and AIDS Strategic Plan 11 (ZNASP) 2011–2015

This document guides the country in the implementation of HIV and AIDS programmes. The ZNASP identifies a set of priorities and strategic actions tied to measurable results, and provide a clear direction for programme implementation. The various strategies developed in the HIV and AIDS sector are guided by the ZNASP. The purpose of ZNASP (Zimbabwe MoHCW & NAC 2011:1) is summarised in the following list:

- Provide a strategic framework that will guide and inform the planning, coordination, implementation, monitoring and evaluation of the national multi-sectoral and decentralised HIV and AIDS response with the aim of achieving “zero new infections, zero discrimination and zero AIDS related deaths”.
- Highlight national priorities, results and targets that all stakeholders and partners will contribute to.
- Establish the basis for Zimbabwe to consolidate its efforts in developing sustainable financing mechanisms for HIV and AIDS response.
- Provide the basis for human and material resource mobilisation and advocacy.

1.1.1.3 Community and Home Based Care programmes for chronic illnesses

Community and Home Based Care (C&HBC) programmes in Zimbabwe have largely been implemented by Community Based Organisations (CBOs) and Non-Governmental Organisations (NGOs) with international donor funding. The HIV and AIDS epidemic galvanised the development and extensive implementation of C&HBC programmes, due to an increase in chronic illnesses resulting from the disease.

Community and Home Based Care has become increasingly important in the past few years due to its ability to provide a continuum of care to the chronically ill (those with diabetes, hypertension and its complications, epilepsy, mental illness, cancer, etc.), people living with HIV (PLH) and those with AIDS, and the elderly.

Community and Home Based Care programmes are also guided by the National Guidelines on Community and Home Based Care for HIV and Other Chronic Diseases (Zimbabwe MoHCW & NAC 2009b). The guidelines provide a detailed and harmonised approach on how C&HBC services should be provided by key service providers; these include planning, implementation, monitoring and evaluation of the C&HBC services. Individuals, families and communities play an essential role in providing care to clients, hence their involvement throughout the process of care is also emphasised in the guidelines, to ensure community participation and sustainability.

1.1.2 The socio-economic situation

The socio-economic situation in the country is significant for C&HBC programmes, in that it determines the availability or the lack of financial resources, along with the capacity for service delivery in health and other related sectors.

1.1.2.1 Economic situation in Zimbabwe

The Zimbabwean economy has been declining since the turn of the century, due to a number of socio-economic and political factors. The effect of the decline in public health is enormous, and it has adversely impacted many aspects of the health care delivery system, resulting in overall deterioration of services. Health facilities and personnel have been overburdened beyond their capacity, and this has affected the quality of service to patients that need care.

The socio-economic problems were compounded by recurrent droughts and the situation was exacerbated by hyperinflation (where the country saw more than a 1 million percentage increase), shortages of foreign currency, and basic commodities such as food, fuel and medicines. The economic decline also resulted in loss of employment and exacerbated poverty (WHO Regional Office for Africa 2009:15). The

majority of families, particularly those residing in rural areas, have been the worst affected by the economic depression. However, hyperinflation ended with the introduction of multiple currencies, and there was a slow recovery seen in the economy between 2010 and 2011. The resultant crisis caused severe food stress to poor and vulnerable households due to lack of agricultural production. Urban areas in the country were not spared the adversity. The increase of poor people living in urban areas has become a global crisis (CSDH 2008:60-61), and should be included in poverty alleviation assessments and national health programme evaluations.

A Mid-Term Review of the 2006-2010 ZNASP (Zimbabwe National AIDS Council 2009:41) states that “chronic illness particularly due to HIV and AIDS causes distress on household incomes and loss of assets, and worsens the poverty afflicting individuals and communities.” Home based care activities have suffered the effects of the socio-economic decline. Hyper-inflation impacted negatively on the procurement of C&HBC programme material and medical supplies, as well as other health care requirements, as prices of goods and commodities escalated beyond planned budgets and available funding.

1.1.2.2 Food security and nutrition

As stated earlier, Zimbabwe has been facing the challenge of severe food insecurity due to a combination of negative factors. Poor harvests resulting from recurrent droughts have prevailed over the past decade resulting in reduced food security. Furthermore, the inability of most rural households to make agricultural purchases including seed, (largely as a result of high prices of agricultural inputs) has been a major factor in food insecurity (CSDH 2008:11). Labour has been reduced owing to chronic illnesses resulting especially from the HIV and AIDS epidemic (Bishop-Sambrook 2004:9). There is widely documented evidence on the effects of HIV and AIDS (Mohammad & Gikonyo 2005:15; WFP 2012:13; Panagides, Graciano, Atekyereza, Gerberg & Chopra 2007:6) on food security and nutrition of PLH and those with AIDS. The authors suggest that political and socio economic circumstances underlie food security in any country. However, some researchers (Opiyo, Yamano & Jayne 2008) have found that due to the fact that agricultural activities have generally been left to women and girls, the burden of home based care, which is entirely their responsibility, renders them ineffective in ensuring food security for their households.

A recent study in Uganda found that food insecurity decreases, while nutritional status improves, among PLH and those with AIDS, a result of improved health status from being on Antiretroviral Therapy (ART) (Weiser, Gupta, Tsai, Frongillo, Grede, Kumbakumba, Kawuma, Hunt, Martin & Bangsberg 2012:182). The study suggests that clients are able to work in their fields or gardens when they become strong and that adequate food and nutrition improves the immune system, enhances adherence to ART and improves productivity and quality of life.

Emergency food assistance is normally provided in some parts of Zimbabwe by NGOs (particularly through the World Food Programme) for clients registered on C&HBC (Panagides et al 2007:20). This has cushioned some clients for short periods of time, but is unsustainable.

1.1.2.3 Sustainable livelihoods of vulnerable communities

The effects of the HIV and AIDS epidemic on the economic capacity of affected households has been debated and documented in several countries over many years (Adedigba, Naidoo, Abegunde, Olagundoye, Adejuyigbe & Fakande 2009:112; Gregson, Mushati, & Nyamukapa 2007:190). In this regard, efforts to establish sustainable livelihoods for clients on C&HBC have been made by organisations implementing the programme throughout the districts of Zimbabwe. A few links have been established with agricultural institutions and relevant organisations to arrange gardening projects for the support of nutrition and these constitute the core of livelihood interventions. Although studies carried out over the past decade in Zimbabwe have shown increased vulnerability of households to poverty and food security as a result of the HIV and AIDS epidemic, Mushongah (2012:575) refutes this assertion on the grounds that coping mechanisms are in place to mitigate the challenges stated above. The author claims in his study that, “a range of determinants contributed to household vulnerability, among them HIV and AIDS, but the epidemic was not necessarily the dominant factor causing household food insecurity and other negative welfare outcomes.” This highlights the complex relationships that ought to be understood between social factors, diseases burden and peoples’ needs.

As a result of the socio-economic instability experienced by so many of its people, the social welfare system in Zimbabwe is overwhelmed with requests for support of vulnerable members of the population from all over the country. Health and education are the main sectors applying for support. Due to the macro-economic factors outlined, the social welfare system fails to provide sufficient support, and people have nowhere to turn to for welfare assistance in the midst of debilitating poverty.

1.2 BACKGROUND INFORMATION ABOUT THE RESEARCH PROBLEM

1.2.1 The source of the research problem

The past two decades have witnessed transition from in-patient hospital admission and care to community and home based care due to the upsurge in chronic health conditions. This was caused by the heightened HIV and AIDS epidemic that has seen its prevalence particularly in Sub-Sahara Africa. This includes Zimbabwe, which has one of the highest HIV prevalence in the world. The UNAIDS HIV and AIDS global situation update reported an HIV prevalence of 18.1% in Zimbabwe in 2005-2006 (UNAIDS 2009:19). Other reports have documented a decline of a range between 16-13.7% in 2007 and 2010 (Halperin, Mugurungi, Hallett, Muchini, Campbell, Magure, Benedikt & Gregson 2011:2; Zimbabwe MoHCW & NAC 2009a:11). The current global situation update reported a reduction in HIV incidence by more than 25% in southern Africa over the last decade (UNAIDS 2012:6). The Ministry of Health and Child Welfare responded to the increase in AIDS related chronic illness by allowing lay people or less qualified community health workers to provide care, as qualified staff emigrated for better remuneration. The lay workers have received little recognition and support from the health care system for their efforts. This has caused them to perform poorly and display limited enthusiasm (Osika et al 2010:10, 15). Consequently non-profit groups have led communities into community and home based care activities. The national health system has provided limited input for C&HBC programmes, due to inadequate resources, leaving private voluntary organisations implementing relatively uncoordinated activities.

If patient's input and goals for good health and care are key to successful health outcomes; it is important that this study examines the related dynamics within community and home based care interventions. It is uncertain whether decisions made

lead to measurable and expected outcomes of quality, effectiveness and efficiency. The reactive modern medical care model is progressively being replaced by community and home based care initiatives, designed in full consultation with service users.

1.2.2 Background to the research problem

This research proposal will investigate the C&HBC programmes in Zimbabwe and focus on the needs of service users as an integral part of health delivery. It is important for service providers, programme implementers and their funding partners to know whether their interventions are meeting the expressed needs of beneficiaries and service users. Studies have documented the value of including patients' or service users' needs in the design and implementation of health care services (Black & Jenkinson 2009:202). There is also a growing belief in allowing patients to interact as partners in the care process, contributing at every stage of their care plan (Holman & Lorig 2000:526; Kironde & Kahirimbanyi 2002:16-22; Thorne, Paterson & Russel 2003:1342).

Community and Home Based Care has become the most preferred form of care in the last two decades, especially in poorly-resourced settings (Hattingh, Dreyer & Roos 2006:95; Shepperd, Harwood, Jenkinson, Gray & Vessey 1998a:1790; Ibrahim, Haroen & Pinxten 2011:235). These authors suggest that increase in community and home health care has been one consequence of the escalation of chronic diseases, especially HIV and AIDS.

1.3 RESEARCH PROBLEM

The number of chronically ill clients being cared for at home is now increasing. Their demands are sometimes complex, especially when living with HIV and AIDS (Zimbabwe MoHCW & NAC 2009b:9). It is unclear to what extent the C&HBC services provide for their needs as service users. There have been suggestions that there is discrepancy between the design of care delivery systems and the needs of chronically ill patients (Wagner, Austin, Davis, Hindmarsh, Schaefer & Bonomi 2001:65) requiring transformation of health systems. Consequently, it is necessary to determine whether communities are adequately skilled to be more active, and not just act as passive end-users of the services provided. In particular, it will be critical to determine the level and intensity of consultations between patients and service providers.

The World Health Report (WHO 2000a:117-122) describes ministries of health as “stewards of [the] health system” in a country, and the report emphasises that, appropriate stewardship “makes possible the attainment of each health system goal; improving health, responding to legitimate expectations of the population, and fairness of contribution. Stewardship must filter through all levels of the health system to maximise the attainment of set goals.” The report goes further to assert that in general, most ministries of health are not cognisant of this fact. The researcher has identified this observation as one key area of concern in C&HBC to be investigated.

In this study, indicators that will determine adequacy of care based on clients’ needs will include: quality of care; and indicators of positive outcomes such as, quality of life; clients physical function and absence of or reduced symptoms. It will be important to establish and differentiate between needs that result in positive health outcomes and quality of life, and perceived needs that have no plausible basis and/or wants. An example of an unreasonable need could be viewed as what the researcher considers to be: a client expecting daily attendance by a health worker for basic procedures such as taking a bath when that task can be assigned to a primary care giver.

1.4 PURPOSE OF THE STUDY

1.4.1 Research purpose

There are two main purposes for this study which are:

To explore whether C&HBC provides services that effectively meet users’ goals in an ever changing social environment and to utilise the findings of the study to develop a guideline for harmonising clients’ needs and expectations with the health delivery system in order to attain specific goals and objectives. These guidelines will focus on three concepts, namely: integration of services; interaction between service provider and service user (service delivery); community capacity and engagement; and harmonisation of health and social services.



1.4.2 Research questions

In order to meet the purposes of the study, three research questions will be answered:

- How does the current delivery of C&HBC meet service users' needs and expectations?
- What is the extent of community participation and decision-making that guarantees attainment of service users' needs and goals, as well as expected health outcomes (the secondary goal of social development)?
- What are the key areas of need that have been identified to develop a guideline for harmonising service users' needs and expectations with the health delivery system for goal attainment?

1.4.3 Research objectives

- To explore and describe the health care needs and experiences of chronically ill service users enrolled in a C&HBC programme.
- To determine whether the C&HBC programme interventions are meeting the intricate goals of chronically ill service users in an ever-dynamic environment.
- To determine the congruency of service users' needs and expectations and the health delivery system goals.
- To use the findings of the study to develop guidelines for harmonising C&HBC service users' needs and expectations with the health delivery system for goal attainment.

1.5 SIGNIFICANCE OF THE STUDY

There is presently limited comprehensive and robust analysis and evaluation of the C&HBC programme that may determine its successes and weaknesses in attaining the goals and needs of clients as end-users. This study aims to bridge this gap. While there are many non-governmental organisations supporting C&HBC activities throughout Zimbabwe, there have been no rigorous and independent evaluations of this nature. This study will pioneer this area of exploration, and provide valuable information for implementing agencies with mandates to identify and meet the health requirements of

chronically ill people at community level through health interventions. An understanding of clients needs, which relate to satisfaction with service provision and subsequent goal attainment, is critical to improving services; since satisfaction with care differs according to context, values and expectations as shown in literature (Hasson & Arnetz 2011:1428).

Through various studies, the needs of chronically ill people have been found to vary depending on the cultural context and geographical area in which people reside. A comparative study of chronically ill patients in Kenya and Scotland revealed vast differences in the needs and experiences of clients in these two countries (Murray, Grant, Grant & Kendall 2003:2; Thorne et al 2003:1349-1350). This suggests that a similar situation is also possible within a single country with diverse cultural and geographical settings, such as there are in Zimbabwe.

The research will inform and influence policy formulation for public health interventions in community and home based care. Findings will expand knowledge and strengthen the capacity of policy makers, donors and implementers to design evidence-informed, community-centred, integrated and sustainable programmes that respond to the health needs of clients.

1.6 DEFINITION OF KEY TERMS

1.6.1 Community

One early definition of “a community” identifies it as a specific group of people, often living in a defined geographical area, who share a common culture, with a shared set of values and norms. (Hattingh et al 2006:211; Issel 2009:109-110). According to Thompson, Coronado, Snipes-Shedra and Puschl (2003:317), community has evolved, from being seen as a social system to the recent emphasis on community as being both a place and a sense of belonging. Communities are no longer necessarily viewed as entire towns or cities, but may be small gatherings, such as religious organisations, workplaces, schools or other entities where people assemble regularly. Conversely, communities may also be larger, such as counties, provinces or states. The changes in definition allow for designing interventions or studies that are contextual and specific to the particular group. Campbell and Murray (2004:189) proclaim that the definition of a

community is both complex and controversial, with most community health services defining it in terms of geographical context.

1.6.2 Community based care

This is care that consumers can access nearest to home, which encourages active participation by the community, responds to the needs of people, encourages traditional community life and creates responsibilities (Zimbabwe MoHCW & NAC 2009b:7). This definition provides a basis for this research. Since the care of the sick often takes place in the home environment, this type of care takes place with support from community structures, and is therefore referred to as community and home based care. This brings out the aspect of complementarity between the home and the community systems.

The WHO (2004:3) defines comprehensive community home based care (CCHBC) as:

an integrated system of care designed to meet the health needs of individuals, families and communities in their local settings. It includes primary prevention, i.e. prevention of health problems and/or diseases before they occur (health promotion and disease prevention); secondary prevention, i.e. early detection of problems or diseases and intervention (curative care and support); and tertiary prevention, i.e. correction and prevention of deterioration, rehabilitation and terminal care (rehabilitative care). It is underpinned by the partnership between health workers, clients/patients and members of the local community. CCHBC can be provided in numerous settings in the community, by various people including health professionals, care assistants, and non-formal care givers such as volunteers and family members.

1.6.3 Home based care

This concept has expanded over the last two decades, mainly as a way of shortening periods of hospital care and reducing health costs. This is any form of care given to sick people in their own homes and also referred to as home health care.

1.6.4 Health need/s

These are essential requirements for a client receiving health care at home as a result of a chronic illness and may include health education, food, shelter, water and sanitation, psychosocial support, and basic nursing care. Client-care-preference and needs for people with chronic illnesses are diverse and complex, and consequently, this study aims to explore those complexities. The issue of health needs is complicated by its correlation with social needs, as these two areas are interlinked. This study addresses all needs (social and health needs) in general, since these needs are interrelated; and it then differentiates between health needs and social needs.

According to Asadi-Lari, Tamburini and Gray (2004:32), it is very difficult to define patients' needs as a result of the wide range of experiences and perceptions that people have. The author believes that health needs have a direct effect on satisfaction with care although the direction is not clear; "for example, patients may have a need for more or better information on some aspect of health. If this need is unmet, it may result in dissatisfaction with services". Therefore, if a particular need is met, people tend to be satisfied with care and vice versa. In the context of this study, needs may therefore be summarised as what people desire to receive from the health care services in order to improve their health status.

1.6.5 Community participation

This is one of the principles underlying primary health care. According to Green (2001:55), there are a variety of definitions of this term since Alma-Ata, some of which are the:

- individual's responsibility of his or her own health
- individual or community involvement in decisions about health care
- individual's contribution to resources or community 'self help' schemes

Other scholars (Thompson et al 2003:323) refer to community participation as "a partnership where both partners have much to give and receive" or community participation as "a process of empowering communities through enhancing people's

own capacity to improve their own lives and to control their destinies” (Hattingh et al 2006:94).

These definitions present challenges, particularly for health care providers who are conditioned to the medical model of health care where imbalance of power between patient and service provider is the norm. Appreciation of the fact that a number of community or social factors influence health and wellbeing, may transform the understanding of community participation in health care among health workers.

1.6.6 Service users

In this study, service users refer to those people who have been diagnosed with a chronic condition and are receiving care within the confines of their homes (primary service user). They are in direct contact with service providers who may be professionally trained, or those trained as community care workers. Secondary service users are the family care givers responsible for providing immediate care to their sick relatives. Secondary service users are often expected to stand in and substitute for the sick relative/client when necessary, in social events as well as at health facilities, particularly when required to collect medicines on behalf of the client. In this study, the expression “service users” will be used interchangeably with client, patient and beneficiary.

1.6.7 Quality of life

This is a measure of clients’ health status. There is a distinction between Health Related Quality of Life (HRQoL) and Quality of Life (QoL) in general. According to Asadi-Lari et al (2004:32), HRQoL restricts consideration to issues that are health service-related, and therefore it overlooks those important social factors that may influence health or be influenced by it. QoL is therefore subjective. According to Asadi-Lari et al (2004:32), it is related to needs and satisfaction, although it is recommended that the three should be measured separately. The authors further suggest that QoL is high when most human needs (not just health needs) are fulfilled, and that they are low when few needs are being satisfied. This implies that focusing only on those needs that can be influenced by health services will give an incomplete picture of the value of these needs to patients. This study is mindful of the issues outlined above.

Various methods and tools that are used to measure health status or quality of life have been documented. Jenkinson (1997:136-139) presents two projects that have used different measures of health status and quality of life respectively:

The Rosser Index: used disability and distress where disability is referred to as “loss of social function assessed objectively and distress classified by subjective evaluation of factors such as pain and physiological condition”.

The EuroQol: measured quality of life through an instrument that measures “five dimensions which are mobility, self care, usual activity, pain and mood”. However, Black and Jenkins (2009:203) further assert that “although clinicians can make objective observations of signs, impairment, and disability, only patients can report on their symptoms and quality of life” and what exacerbates or controls them.

Quality of life is therefore the perception of being able to achieve certain aspirations in life as a result of good health. Raphael, Steinmetz, Renwick, Rootman, Brown, Sehdev, Phillip & Smith (1999:201) describe quality of life as “an approach that focuses on the perceptions of community members of what makes life good or not good for them.” The authors further describe nine domains of quality of life in detail, as well as quality of life being the sense of “being”, “belonging” and “becoming”.

1.6.8 Home based care kit

A small carrier that contains medical supplies and basic nursing commodities such as: disinfectants, gloves, soap, paracetamol (pain relief medicine) bandages and antiseptics among others. Care givers are equipped with these items to ensure infection control by encompassing universal precautions (infection control) standards during basic nursing care. These kits should be replenished regularly and supplied through health facilities.

1.6.9 Experience

This refers to an episode that affects one's health and health care and brings about a need that ought to be satisfied.

1.6.10 Perceptions

Is an individual's judgement or opinion of the care provided. It also serves as a type of outcome measure of care, and is related to how patients feel about the care that they receive according to their needs. Measurement of perceptions helps to restructure the provision of care based on feedback obtained from clients and other key informants.

1.6.11 Primary care giver

This is often a family member who works closely with the C&HBC team to provide basic care and support for a sick client or relative.

1.6.12 Secondary care giver

This refers to what is often a trained volunteer, who works with communities and families to provide basic treatment and occasional basic nursing care to clients on C&HBC; who may also refer them to health facilities or professional service providers for other services.

1.6.13 Words used interchangeably in the study

- **Health facilities** – clinics and/or hospitals
- **Primary care giver** is also referred to as **family care giver**
- **Primary** and **secondary** care givers are at times referred to collectively as **care givers** in the document
- **Secondary care givers** also referred to as **community health workers**
- **Patient** also referred to as **client** or **service user**
- **Participants** also referred to as **respondents**
- **Health service providers** or health workers are **community health workers** and **health professionals** collectively.

1.7 FOUNDATIONS OF THE STUDY

1.7.1 Metatheoretical assumptions

The first assumption presupposes that if community and home health care is effective, there should be synergy between the client's goals and those of the service provider. Generally, the users of health services (especially those from poor backgrounds) are hesitant about active participation in their health care plans and activities, leaving all decisions to the service provider. Users tend to accept what is prescribed for them without questioning the benefits and risks of those decisions, or comparing what is suggested with their own treatment goals and expected outcomes. Moreover, C&HBC programmes should be led by a deeper appreciation of the role that health plays in human, social and economic development.

The research will be based on the principle demonstrated in the framework below.

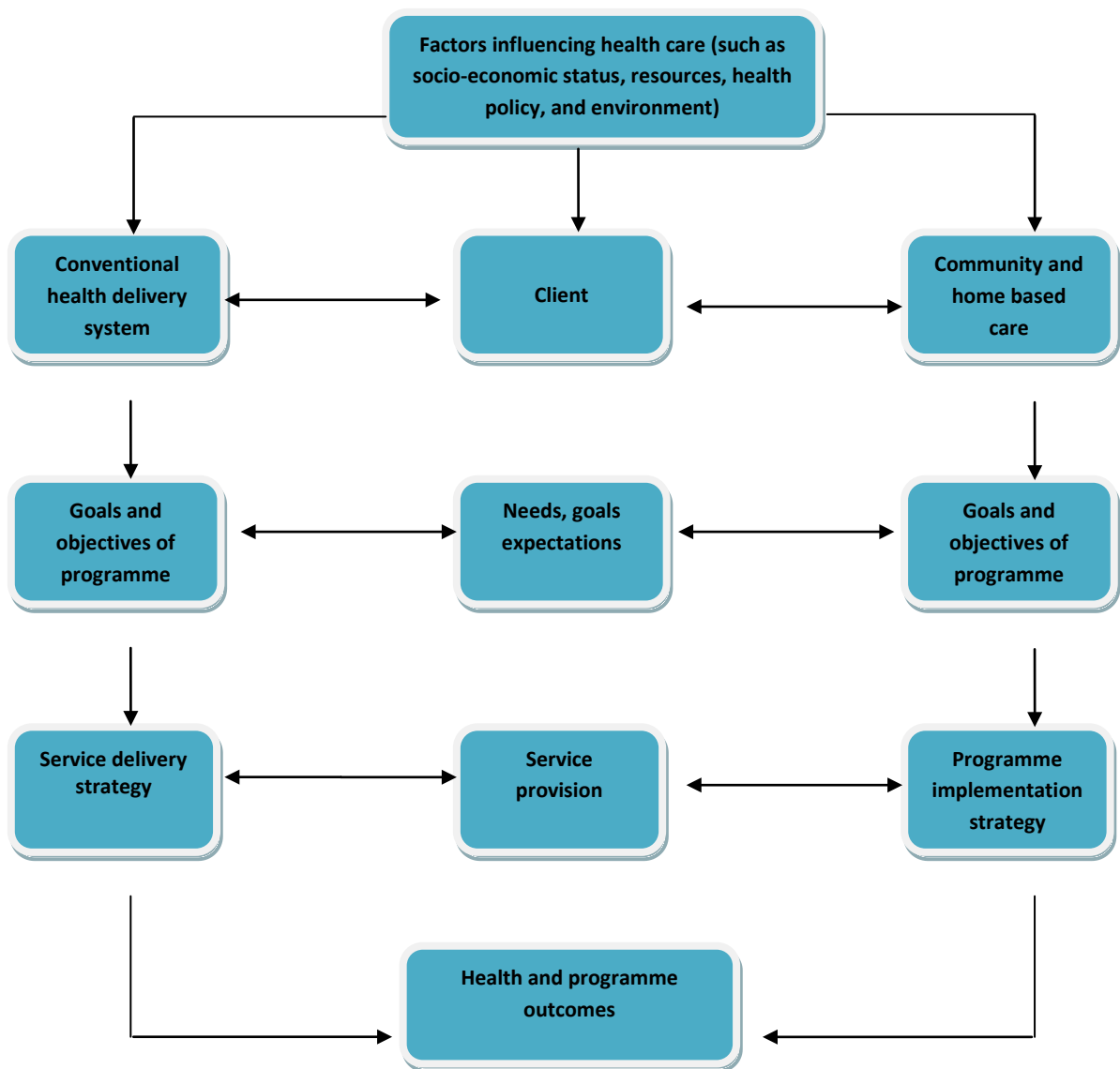


Figure 1.1 Framework for the provision of goal-oriented health care

This framework assumes that goal-oriented health care takes into consideration all aspects of the clients' life and that goals have to be set at all levels of service delivery. The health systems and the C&HBC programme should have goals and strategies in place. This is in addition to clients' goals, which should be in line with those of the health care systems. This harmonised approach enhances effective service provision.

1.7.2 Imogene King's conceptual framework and theory of goal attainment

This framework and theory underpin this study in its investigation of the attainment of C&HBC patients' and programme goals with reference to clients' needs and

expectations. King's framework and theory have been applied successfully in several nursing care situations and in research.

Imogene King's conceptual framework (King 2010:149) refers to three interactive systems. These systems are the individual or personal; the interpersonal or group; and the social or society.

The theory of goal attainment illustrates the importance of interaction, perception, communication, transaction, self, role, coping, growth, development, time and personal space. These components are extracted from the personal and interpersonal systems described above. The goal of the nurse is to help patients promote and regain health through mutual goal setting for effectiveness of care (King 2010:150; Goodwin, Kiehl & Peterson 2002:239). King's theory of goal attainment emphasises that both the nurse and the patient bring useful information and knowledge to a relationship and interaction (King 2010:150).

The framework is applicable when pursuing comprehensive health care and facilitating interaction between interpersonal systems, the social systems, the individual and nurse for effective transactions (King 2010:150; Goodwin et al 2002:239). According to King (2010:150) interaction between patient and nurse as a communication meant for exploring options and setting mutual goals as part of health care. However, the interpersonal interaction is influenced by other systems, such as the society and personal systems.

Application of this framework and theory will be used where relevant throughout the study analysis and documentation of findings.

1.8 RESEARCH DESIGN AND METHODS

This is a cross sectional explorative and descriptive study of the C&HBC service using a combination of qualitative and quantitative methods (David & Sutton 2007:38). The use of multiple mixed methods is known to provide an examination of both process and outcome (Tucker, Van, Teijlingen, Phillip, Shucksmith & Penney 2006:185-186). According to David and Sutton (2007:44), there is no significant distinction between qualitative and quantitative methods, as the two provide synergy and added benefit to

social research. Each method has its own limitations, and therefore mixed methods ensure robust results, due to the possibility of triangulation, to confirm findings from the various sources of information (Issel 2009:480-481). By triangulating information from multiple sources, it will be possible to increase understanding of the dynamics between attainment of service users' needs and goals and the prescribed health service delivery.

Methods of data collection will include structured questionnaire interviews, unstructured questionnaire guides and focus group discussions. Information will be gathered from health providers and implementers; policy makers, service users, community leaders and family members; community care givers, and representatives of key implementing organisations.

Several studies have been carried on assessment of patients needs as a means of evaluating programmes (Boryc, Anastario, Dann, Chi, Cicatelli, Steilen, Gordon-Boyle, Singh & Morris 2010:485; Jenkinson 1997:85-98; Nunez, Armbruste, Phillips & Gale 2003:26; Corazzini-Gomez 2001:740-750). These studies have used different tools and covered a wide range of outcomes of measure of patient needs and satisfaction. The researcher will adapt and utilise previously developed and applied tools for outcome measurement of clients' health status.

While this study will select and adapt variables for assessment from other studies (Tamburini, Gangeri, Brunelli, Beltrami, Boeri, Borreani, Fusco-Karmann, Greco, Miccinesi, Murru & Trimigno 2000:33; Figuero, Luque, Martin, Sagrado & Bouza 2011:26; Mpinga & Chastonay 2011:65). Partial assessment of patient satisfaction will be conducted, since there is likely to be a link between patients' satisfaction and their needs (Asadi-Lari et al 2004:32). However, Issel (2009:312) dismisses this notion in asserting that participant satisfaction is "an element of process evaluation rather than a programme outcome." The writer further describes the challenges of developing culturally sensitive and appropriate measures of satisfaction, along with the challenge of differentiating satisfaction and expectations (Issel 2009:313). For this reason, this study will adapt and incorporate a small number of questions from existing and tested satisfaction measures of assessment and take into account the socio-cultural dynamics of the study participants.

As part of contextual analysis, a number of variables will be examined and analysed, and comparisons made between them. Demographic characteristics will be used to test for differential effects based on age, gender, location, and socio-economic status of individuals and households.

1.9 SCOPE OF THE STUDY

1.9.1 Setting

Study sites will be stratified according to urban and rural settings. High density (low income neighbourhood) suburbs in the city of Harare and Marondera town and one rural district of Mashonaland East Province will be selected for the study. The different sites will allow for an in-depth analysis by socio-economic dynamics. The sites will be of communities where a formal C&HBC programme is being implemented.

Migration between rural and urban areas is substantial as a result of high unemployment rates in the country, and as people search for livelihoods. There is widespread rural to urban migration and general poverty observed across Zimbabwe. It is likely that differences in the social dynamics experienced by participants in the two areas will generate useful insights. Two organisations implementing C&HBC in these areas and that are members of the Zimbabwe AIDS Network (ZAN) will be identified. ZAN is an umbrella organisation of all AIDS Service Organisations in Zimbabwe, and provides them with capacity building, promotes information sharing and effective mobilisation and use of resources including lobbying and advocacy. The researcher will work closely with these organisations that will provide access into the selected communities.

1.9.2 Population and sample selection

1.9.2.1 Study population

The study population will consist of the following:

Primary population: Chronically ill persons enrolled in a formal C&HBC programme. Primary care givers will be enrolled in the study.

Secondary population: Stakeholders, namely, health institution managers, non-governmental organisations' implementers of home based care programmes, Ministry of Health and Child Welfare authorities, community health workers and community/local leaders.

1.9.3 Sampling

The researcher will use purposive selection of clients within the identified communities. Purposive sampling is recommended for qualitative studies, as it allows for flexibility in determining the appropriate participants for the phenomenon under investigation (David & Sutton 2007:152; Issel 2009:482; Usherwood 1996:29). Furthermore, purposive sampling of organisations implementing C&HBC programmes to facilitate access to clients will be undertaken. Sampling will be made in collaboration with the selected C&HBC programmes' implementers working in selected districts and villages. Primary participants (chronically ill clients) who are eligible and willing to participate in the study will be identified through community health workers residing within the communities.

According to David and Sutton (2007:152-153), sampling and sample size estimation for qualitative observational studies is based on the researcher's knowledge and experience of the most appropriate respondents to select. Issel (2009:482) and Usherwood (1996:29) as well as Greenfield (1996:131) suggest that a sample size could be based on an estimate of the number of participants that will provide saturation (redundancy) of information required to make valid conclusions. Other authors (David & Sutton 2007:153-154; Fisher, Foreit, Laing, Stoeckel & Townsend 2002:68-69; Issel 2009:483) also suggest a number of other considerations in determining sampling method and sample size, such as the level of analysis required; the availability of resources for the study; the study design; and the health outcome being investigated. The above considerations will be taken into account in designing this research. Notwithstanding the shortcomings of purposive sampling, the researcher will ensure that the data collected is robust and sufficient to make valid judgments.

1.10 STRUCTURE OF THE THESIS

The research study will be structured in the following manner:

Chapter 1: Orientation of the study

This chapter presents an overview of the entire study. It highlights the background to the study through the description of the health system in Zimbabwe, the statement of the problem, research purpose and questions. This is followed by a presentation of the research design and method, scope of the study and conclusion.

Chapter 2: Literature review

This chapter focuses on presenting some of the publications reviewed, as well the views of other researchers on the topic under study. The researcher reviewed available literature including “grey” literature, for deeper meaning and increased understanding of the research topic, along with methods that could be applied for study validity and precision. The literature review contextualises the study and the design of appropriate questionnaires and question guides.

Chapter 3: Research design and method

This chapter will take the reader through the research design and methods employed during the study. The setting, population and sampling methods, as well the data collection and analysis plan of the study are described in detail. The relevant ethical issues guiding the study are also presented in this chapter.

Chapter 4: Analysis, presentation and description of the research findings

In this chapter, additional details on data management and analysis are presented. More importantly, the research findings are presented through graphs, tables and direct quotations from respondents. An overview of the research findings concludes the chapter.

Chapter 5: Discussion

This chapter presents further analysis and discussion of the findings presented in chapter 4. The discussion links literature review with study findings.

Chapter 6: Evidence informed operational guidelines for an integrated approach to the mitigation of chronic illnesses

This chapter of the research study provides an evidence-informed guideline for the development of integrated C&HBC programmes with social services and other health services. The guideline is a set of proposals that are based on key findings from the research.

Chapter 7: Conclusions and recommendations

This chapter contains conclusions prepared after the analysis of findings. The chapter discusses the theoretical framework, limitations, and implications of findings for nursing practice and provides recommendations for future practice and research.

1.11 CONCLUSION

The foundation for this qualitative exploratory and descriptive study of participants involved in C&HBC programmes in rural and urban Zimbabwe was presented in this chapter. The purpose of the study is to explore whether service users' needs, expectations and goals are taken into consideration in service delivery. The approach employed in this study is of multiple methods, and the review of different sources of information. A non-probability purposive sampling is proposed in order to achieve broad insight of the phenomenon under study. The results of the study will add to existing knowledge on the design of C&HBC programmes that suit the recipients' complex individual needs.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

A survey of the literature for this study is aimed at revealing the dearth of systematic and comprehensive research on the needs and expectations of service users in C&HBC. It will also reveal efforts that have been made in improving the quality of care provided in community and home settings. There is a broad literature available of studies that have been carried out on “long-term care and coping with chronic diseases”, mainly for the old aged in institutional settings, and within developed countries (Perez 2011:9-10; Mayer, Williams, Wagner, LoGerfo, Cheadle & Phelan 2010:4; Schoen, Osborn, How, Doty & Peugh 2009:13). Long-term conditions are increasingly becoming prevalent in developing countries, but few studies addressing the needs and goals of recipients of care for diverse age groups have been carried out. The increase in long-term illnesses has necessitated a shift from care within hospitals and nursing homes to C&HBC as the most preferred, effective and efficient health delivery option.

The WHO states that chronic diseases (from the communicable and the non-communicable) are escalating globally (WHO 2008d:2). The realisation that these lifestyle diseases such as diabetes, hypertension and heart problems are escalating and require greater attention has advanced in recent years. Other commonly reported chronic conditions include: cancers, arthritis, mental disorders, chronic pulmonary diseases, and physical disabilities. Health systems are challenged by these threats and reforms are required in order to manage the new developments. The WHO (2008d:2) further states that an estimated 80% of deaths due to chronic diseases are occurring in low and middle-income countries, and there are approximately 16 million deaths involving people less than 70 years of age. These deaths are projected to increase by a further 17% over the next 10 years.

Less attention has been paid to non-communicable diseases (NCDs) in low and middle income countries over the years than on communicable diseases such as HIV or diarrhoeal diseases (Daar 2010:306). However, the WHO has taken the issue seriously and actively advocates for national health authorities to address the problem before it becomes a crisis.

The high prevalence of HIV and AIDS, particularly in Sub-Saharan Africa, has also contributed to increased disability and dependency on community and home-related care and other forms of social care. In this regard, concerted efforts are required to continuously revise the health policy to suit these emerging new challenges. In South Africa for an example, the burden of chronic illnesses is seen to have risen since the end of apartheid in 1994 (Mayosi, Flisher, Lalloo, Sitas, Tollman & Bradshaw 2009:934). This rising burden, partly exacerbated by the increase in HIV and AIDS incidence, calls for strengthening of health systems and service delivery at all levels. The common risk factors are the changes in lifestyles to match those of the industrialised world, as well as the poor socio-economic conditions that make people more vulnerable to poor health, particularly when due to a lack of access to better living conditions and medical advice (Mayosi et al 2009:936).

Zimbabwe reports a high prevalence of communicable and non-communicable diseases (Zimbabwe MoHCW & WHO 2009:5) like many other countries. This has been the result of a high prevalence of HIV and AIDS, as well as the general change in lifestyle and eating habits as people adopt more western styles of life. Currently, Zimbabweans have adopted sedentary lifestyles and consume less organic and more refined foods than in the past. This and other behavioural changes places them at risk of chronic diseases related to quality of food consumption and lack of exercise.

2.1.1 Chronic illness

Chronic illnesses are associated with long-term and incurable illness, in contrast to acute illness, which is often short-term and curable. The meaning of the term chronic illness has shifted over the years in the context of a changing health care delivery system, now referring to “long-term chronic conditions” (Denny & Earle 2009:3). The new meaning takes into consideration that when a patient moves from an acute state, they enter into a phase of managing and living with the effects of the condition (not

necessarily illness) for a long period of time. However, there is no agreed upon definition among all scholars in this area and the term chronic illness continues to be used. According to Denny and Earle (2009:3), the British National Health System is reported to define long-term conditions as “those that currently have no cure, but can be controlled or contained by medication or other interventions”.

From this background, chronic illness will also be referred to as long-term conditions in this study. This takes into account communicable and non-communicable diseases, which can be chronic, as exemplified by HIV and AIDS, diabetes and heart disease respectively. Other forms of chronic illnesses which are often included in the home and community care environments as part of the C&HBC programme in Zimbabwe, range from epilepsy, respiratory diseases, hypertension, mental illness, disability, rheumatoid arthritis to skin disease (psoriasis).

2.1.2 HIV and AIDS as a widespread chronic illness in Zimbabwe

Zimbabwe diagnosed its first case of HIV in 1985 (Looking back, mapping forwards 2007:29). From that time onwards, the government gradually introduced interventions to prevent the spread of the disease. Zimbabwe has one of the highest rates of HIV prevalence in Southern Africa, with an estimated 1.2 million PLH and those with AIDS (Zimbabwe MoHCW & NAC 2009a:21; Zimbabwe MoHCW, NAC, World Bank & UNAIDS 2011:8). It has been documented that the Zimbabwe HIV epidemic displays the general trend that is related to age and gender pattern of all Southern African countries. Overall, HIV prevalence in adult women aged 15-49 is 21.1%, significantly higher than prevalence in men aged 15-49, at 14.5%. It is significantly higher in women than in men at younger ages and significantly lower at older ages (Zimbabwe MoHCW, NAC, World Bank & UNAIDS 2011:19). The gender pattern is a result of the gender imbalances existing within a generally patriarchal society. The unequal status of women to men makes them more vulnerable to HIV infection through their inability to assert and protect themselves. The Zimbabwean HIV prevalence is similar across all 10 provinces and regions as well as rural-urban areas, rendering an even spread of the epidemic in the country (Zimbabwe MoHCW, NAC, World Bank & UNAIDS 2011:15).

A positive development, however, is that Zimbabwe is one of the few countries where in recent years, the prevalence of HIV has shown a reduction from 26.4% in 1997 to

14.3% in 2009 (Zimbabwe MoHCW & NAC 2009a:16; Zimbabwe MoHCW, NAC, World Bank & UNAIDS 2011:12). The HIV prevalence is currently estimated at 13.7% (Zimbabwe MoHCW & NAC 2009a:2&31).

The decline in HIV prevalence in Zimbabwe has been attributed to several factors such as sexual behaviour change in the form of reduced casual sex, and a reduction in number of sexual partners as a result of intensified health education campaigns (Zimbabwe MoHCW & NAC 2009a:28).

HIV and AIDS and Tuberculosis (TB) are now classified among the most prevalent chronic illnesses in Zimbabwe and worldwide, as a result of co-infection. HIV and AIDS encompass all the features of chronic diseases (Stuart 2008:12) and the principles for managing the problem are similar to those of other chronic conditions. C&HBC programmes have also focused on tuberculosis, the result of which is that most literature documenting home based care for HIV and AIDS clients includes information on TB. It is therefore envisaged that this study will gain its knowledge and understanding mainly from the experiences of PLH and those with AIDS and from organisations implementing HIV and AIDS focused programmes. Moreover, such programmes have resolved to be inclusive of all chronic conditions when dealing with HIV and AIDS, in order to avoid discrimination within communities.

2.1.3 Other issues associated with chronic long-term conditions

There are also other complex and serious issues that are a result of long-term conditions, such as social stigma and discrimination, as well as disability or impairment of varying levels. Stigma affects the decisions and thoughts of chronically ill persons making them less able to articulate their needs and expectations (Thupayagale-Tshweneagae & Mokomane 2012:29). When people are diagnosed with a chronic or terminal illness such as cancer or HIV, they often go through various emotions, which vary from person to person and hence require different interventions. Individuals experience common stages that include shock, denial, helplessness/hopelessness, anxiety or fatalism, and eventually acceptance and a sense of 'fighting spirit', (Mgutshini 2011:56). These need to be taken into consideration in the care and recovery of the client. Chronic illness causes disruption of the client's life in terms of changes that have to be made in life-plans and daily living. These may also include a loss of self identity

and self esteem (Denny & Earle 2009:15-16) all of which complicate delivery of services.

A small-scale study reported by White and Harris (2001:112-131) revealed how the needs and expectations of the elderly clients may be a mismatch from what is available and predetermined by the health care system. The study reveals that needs which determine quality of life differ from one individual to another with the same condition or impairment. Another study (De Guzman, Santos, Santos, Santos, Santos & Santos 2012:309) exploring the concept of, expectations and frustrations with care, experienced by the elderly suffering from chronic illness, revealed the additional complexities of chronic care. It showed the subjective nature of expectations and frustrations with care and the caring process from the patients' perspective. The patients' frustrations and expectations ranged from professional knowledge and skill, communication skills, availability of facilities to financial constraints.

Certain ingredients are essential to effective C&HBC, such as the importance of responding to the clients' own definition of need, and also the attention paid to maintaining personal identity and self esteem.

It is common practice that all forms of illness are treated using the medical model of care, which tends to emphasise the acute medical problems faced by people. White and Harris (2001:178) suggest that the social model is preferred, since "it is person centred and encompasses the socio-cultural, environmental factors as well as the civil rights of service users". The authors describe the medical model as "oppressive" due to its restrictiveness and failure to embrace a person holistically. Denny and Earl (2009:2-8) also reiterate that if chronic illness is viewed from a sociological perspective, it embraces not only the pain and discomfort experienced by a person, but also embraces the societal, environmental and interpersonal relationships and factors around the ill person. This view is embraced throughout this study.

2.2 COMMUNITY AND HOME BASED CARE

The WHO study group on long-term home based care (WHO 2000b:1) define long-term home based care as "an integral part of health and social systems which include activities undertaken for people requiring care by formal and informal care givers";

furthermore it states that “the need for long-term care is influenced by changing physical, mental and/or cognitive functional capacities that are influenced over an individual's life by the environment.”

The above definition captures the importance of the range of needs an individual client and family are likely to face as well the implication that there should be some agreement on the range of services provided. This study will investigate to what extent comprehensive and systematic assessments of service users' needs are carried out and the practicality of agreements made for goal attainment.

2.2.1 Evolution of Community and Home Based Care

Globally, home based care was seen as an extension of hospital care, that provided a blend of both social and medical services in order to address the needs of long-term and terminal illnesses, which have been gradually escalating (Epping-Jordan 2005:86). The service was initially seen and provided as a team service by a range of professionals and health experts, who visited patients at home following their discharge from hospital.

The concept of C&HBC is also not new in Southern Africa. It dates back to the 1980s, when chronic illnesses such as cancer were nursed at homes. The concept became wide spread with the emergence of the HIV and AIDS epidemic.

Home based care has always been a common feature in Africa and Zimbabwe as a result of chronic afflictions. Affluent lifestyles have meanwhile brought about related health conditions such as diabetes, hypertension and heart disease resulting in the upsurge of chronic illnesses and an increased demand for C&HBC. This mode of care is likely to remain in place for a long time to come. The reasons for this are the lack of affordability of hospital user fees for the majority of the population, due to widespread poverty and the poorly-resourced health sector, which adversely impacts upon service delivery. Patients are discharged early for further care within the home environment.

Literature on home based care reveals that generally, C&HBC was initiated by faith-based organisations out of compassion by church groups on PLH and those with AIDS and other chronic conditions, despite their limited resources (Agadjanian & Sen

2007:365). These groups worked closely with family carers, relatives and neighbours in providing spiritual, physical and psychological support to the sick and their families as part of the continuum of care. Gradually, CBOs and NGOs began to provide support to the growing initiatives.

The practice of home based care was also initiated in Zimbabwe soon after the country's independence in 1980, when Primary Health Care was adopted as a strategy to ensure equity and access to health services for all citizens. The majority of clients enrolled in home based care programmes were those with chronic illnesses such as cancer, mental illnesses, TB and stroke from hypertension. However, with the impact of the HIV and AIDS epidemic in the early nineties, home based care was overwhelmed by the number of clients suffering from the effects of HIV and AIDS than from other conditions (Zimbabwe MoHCW & NAC 2009b:2). This state of affairs has persisted to date, although with the scaling up of ART there has been a shift from the basic nursing care of people with AIDS-related conditions, to ongoing treatment and support for adherence to medication for those on ART (Wringe, Cataldo, Stevenson & Fakoya 2010:358; Ogden, Esim & Grown 2004:33, 47). Some donor funded C&HBC programmes have scaled down their support in the last few years citing an increase in those on ART resulting in fewer bedridden clients as one of the main reasons.

An increase in C&HBC clients and changes in the type of profile of these clients triggered the need for a review in the C&HBC strategy, particularly in light of the inadequacy of professional staff to provide the service. Direct service provision was therefore assigned to community health workers, who were trained (for periods ranging from 1-2 weeks). Service provision was offered in basic nursing care as well as basic counselling, and was based on the ability of community health workers to assess clients for pain, to provide pain relief, and to refer clients to health facilities.

Many home based care initiatives were set up in different communities. These were implemented by a variety of local groups as a response to the burden that communities faced due to chronic illnesses resulting from the spread of the HIV and AIDS epidemic. Therefore, there was a growing need for guidelines to standardise the care approach of the numerous ventures in order to improve coordination, as well as monitoring and evaluation activities.

It was only upon realisation of the disarray of the home based health care situation in 2002 that the WHO developed a global Policy Framework for C&HBC for Resource Limited Settings to create and sustain a comprehensive care strategy for home based care clients (WHO 2002). Although this framework was a good starting point in ensuring a coordinated response, it was found lacking in the way it addressed social issues such as gender disparities and the welfare of care givers.

2.2.2 The role of community and home based care in service delivery

The Zimbabwe National AIDS Policy commissioned in 1999 describes C&HBC as “an extension of the health care delivery system to be fully developed and supported as an essential component of the continuum of care for PLH and those with AIDS as well as those with other chronic and terminal illnesses” (Republic of Zimbabwe 1999:14).

C&HBC is viewed by clients and their families as a lifeline for chronically ill patients, whose numbers have increased over the years. Patients can receive care and support in their own environment and at home with assistance also being provided by trained community health workers. Through C&HBC, hospitals are relieved of the burden of care for patients with long-term illnesses, and this eases pressure on bed-occupancy in often over-crowded hospital wards. It has been stated that “significant numbers of the chronically ill have accessed C&HBC over the past five years in Zimbabwe. The number of chronically ill individuals receiving care increased from 453,957 in 2007 to 489,320 in 2008 and 697,647 at the end of 2009” (Zimbabwe MoHCW & NAC 2011:46).

According to the Zimbabwe C&HBC policy and guidelines, the needs of chronically-ill clients are classified as: the need for quality care, the need for family and social support systems and the need for client and family involvement in decision-making and planning (Zimbabwe MoHCW & NAC 2009b:2; Republic of Zimbabwe 2001:6-9). Other needs have emerged, mainly as a result of socio-economic challenges experienced in Zimbabwe and in many other non-industrialised countries. Those needs evolve around livelihoods and food security, which are key components of human survival, especially where families are faced with a long-term illness. Long-term illnesses tend to occur among the elderly and also among breadwinners, who are the source of livelihoods within families. The C&HBC guidelines (Zimbabwe MoHCW & NAC 2009:2) state that home based care can also enhance preventive measures, through health education and

help strengthen the existing health care systems and empower the community to look after its own sick people.

An Access to Health Care Services Study (Makuto & James 2008:34-35, 46) conducted in Zimbabwe; reports that there are governance systems developed at district level to ensure community participation and involvement in health service delivery and related matters. It was, however, observed that the performance of these structures, which include development committees and village health committees, is minimal and fraught with controversy. However, in these cases, the communities feel on the one hand less involved in decision-making on health-related issues, while on the other hand, health workers are unclear of policy guidelines set by Ministry of Health and Child Welfare, including what each party's responsibilities and involvement ought to be.

2.2.3 Services offered in Community and Home Based Care

Although home based care started long before the development of policies, strategic frameworks and guidelines, these were later developed to standardise practice and guide implementation. The National HIV and AIDS policy mandated the development of National C&HBC guidelines and a referral and discharge plan for clients benefitting from the intervention, to ensure full benefit and utilisation of the service. A number of other national guiding frameworks such as the Zimbabwe National AIDS Strategic Plan 2006-2010 (revised to operate from 2011 to 2015) were developed, in order to ensure a coordinated multisectoral response. In line with the National C&HBC Policy, the Zimbabwe National Guidelines for home based care services state the service users' needs of home based care to be the following: physical support; emotional support; social support; spiritual support; legal support; economic support and symptom/pain management.

A comprehensive C&HBC package recommended by MoHCW in Zimbabwe is envisaged to consist of prevention, treatment, care and support services, which integrate with referral services. Such an approach is meant to ensure a continuum of care and is a comprehensive response provided at hospital and home and encompassing the needs identified above (Zimbabwe MoHCW & NAC 2009b:7).

Lichtenberg (2012:95) explored whether home based care could be considered a substitute for hospital care, or whether it has other roles in service delivery. The study concludes that home based care merely reduces the length of hospital stay, as patients are discharged for further care and treatment at home. However, home based care ensures a continuum of care by various stakeholders who have an interest in the wellbeing of the client.

It is also generally assumed that home and community care is cheaper than facility-based care, although some scholars have refuted these claims (Ogden et al 2004:6; Jaffar, Amuron, Foster, Birungi, Levin, Namara, Nabiryo, Ndembi, Kyomuhangi, Opio, Bunnell, Tappero, Mermin, Coutinho & Grosskurth 2009:8). Some studies have, however, demonstrated the cost effectiveness of home-based care programmes (Moalosi, Floyd, Phatshwane, Moeti, Binkini & Kenyon 2003:S80-S85) as well as the reduction in hospital admissions as a result of home based care programmes. There has not been sustained consensus on the issues raised above (Mayer et al 2010:4). Moreover it is also suggested that costing of home based care services should acknowledge the diversity of implementation strategies. It is also suggested that the diversity of clients' conditions and needs, as well as the value of services provided by mainly female volunteers as care givers, should also be taken into consideration when costing services (Musau, Chanfreau & Kyomuhangi 2005:4-7; WHO 2004:40; Thabethe 2011:790; WHO 2002:20). Without comprehensive studies on this aspect, it would be difficult to reach firm conclusions on the issue.

It is also assumed that patients prefer the familiar home environment with easy access to family and friends, as well as other amenities. However, there is an array of needs that long-term care patients require at home. These go beyond medical care and nursing care, to include household chores and other social requirements (King 2000:2). It is not known to what extent clients and their families have the capacity to meet these needs.

The home environment is not always conducive for care of people with various impairments and special needs. This is all the more so among poor families and those residing in rural areas, where basic amenities such as toilet facilities and running water are unavailable. A study investigating the housing conditions of patients enrolled in a home based care programme in Botswana (Fidzani & Gobotswang 2012:51) found that

many C&HBC clients are subject to housing conditions that pose a health hazard and can therefore have serious implications on health outcomes and quality of life of those who are chronically ill. The study therefore recommended thorough assessment of environmental conditions into which patients are discharged, in order to provide advice and if feasible, to support the improvement of living conditions. A small but significant number of clients and care givers in this study raised the issue of housing as a critical need.

Since this study will be investigating clients' needs for community and home based care, it is important to take into account the type of needs that exist. Issel (2009:114) underscores the importance of "understanding the characteristics of needs in relation to the population of interest for successful health planning" These needs are described as: "expressed needs (expressed through the demand for services), normative needs (lack or inadequacy as defined by the health provider), perceived needs (experienced as lack by the client) and relative needs (comparative needs)." This study will be guided by the above principles in making conclusions.

The remaining part of this chapter will review, summarise and discuss three aspects related to the study which are: (1) the strategy and goals of community and home based care, (2) the needs and expectations of community and home based care service users and, (3) the community development aspects of public health as it relates to home based health care. The chapter will confine discussions to those studies that address issues that are relevant to this investigation and to those which are guided by the research questions and objectives of this study.

2.3 THE ZIMBABWE COMMUNITY AND HOME BASED CARE STRATEGY AND GOALS

Following the introduction of C&HBC in Zimbabwe, it became imperative that goals and strategies were put in place for the programme to operate efficiently and effectively. Many governments that recognised the importance of C&HBC as an essential part of their health delivery system, such as in Botswana, South Africa, Zambia and Zimbabwe, as well as others in East and Southern Africa, developed comprehensive C&HBC policies, standards and implementation plans. These strategies are guided by the WHO's Comprehensive Community and Home Based Health Care Model (WHO

2002:6) and the Community Home Based Care in Resource-Limited Settings Framework for Action (WHO 2004:10).

The overall goal of C&HBC has therefore been generally adopted as the provision of comprehensive care services at home and at community levels, in order to meet the physical, psychological, social, spiritual and material needs of chronically and terminally ill clients (Family Health International 2004:8; Zimbabwe MoHCW & NAC 2009b:19).

According to WHO (2002:6), “community home based care is defined as any form of care given to ill people in their homes. Such care includes physical, psychosocial, palliative and spiritual activities. The goal of C&HBC is to provide hope through high-quality and appropriate care that helps ill people and families to maintain their independence and achieve the best possible quality of life”.

C&HBC programmes are a platform to provide a continuum of care through a range of prevention, treatment, care and support services provided by and through inter-sectoral collaboration and networking. A continuum of care ensures that a diverse range of health services is provided by different stakeholders as and when required, and that referral of clients is made for appropriate services. A continuum of care is holistic support rendered to ill persons and their families from various settings, such as the home, community agencies, clinics and hospitals. It encompasses the provision of both medical and non-medical care and activities.

2.3.1 Community and home based care models

The idea of using models of care is to meet the various needs and goals of C&HBC service users in their homes by various agencies or providers of service, using standard or similar systems. A comprehensive model of care should provide primary prevention (health promotion and disease prevention), secondary prevention (curative care and support), and tertiary prevention (correction and prevention of deterioration, rehabilitation) (Pau 2008:77).

There have been ongoing changes in the models used as a result of the dynamic environment in Zimbabwe. These changes were necessary if home based care was to

remain effective and responsive in the relatively unstable economic environment. This unstable environment had negative impact on the health systems management and health service delivery, and rendered them largely inefficient. The engagement of volunteers as care givers was adopted as a home based care strategy, in order to reach as many people as possible. This was in contrast to earlier initiatives, which were either faith-based (church members engaged as care givers) or linked to kinship with families caring for their own relatives.

The following are traditional models that have evolved in home based care, as described by Ogden et al (2004:3, 10-14):

Linked care – usually provided by volunteers or professionals who are linked to NGO managed programmes or health facilities.

Unlinked care – usually provided by unpaid and untrained family members and friends.

Integrated C&HBC Model (Linked C&HBC)

This model links a range of service providers with patients and their families i.e. volunteer care giver, hospital, clinic, NGO, family and the patient. It allows for referral between partners and ensures shared resources and capacities.

Single Service Model (Linked C&HBC)

This model has one service provider such as a hospital, clinic, NGO or Faith Based Organisation (FBO). The service provider recruits, trains and links volunteers with patients and their families at home.

Informal HBC Model (Unlinked C&HBC)

Families are assisted to care for their sick relatives in their homes with informal assistance of their own social networks.

The following table shows the various models adopted and used in different settings:

Table 2.1 Community and home based care models

Type of model	Shortcomings	Advantages
Hospital outreach (<i>Hospital staff provide outreach care services</i>)	Costly; may be stigmatising; delayed services; strong focus on medical care; no direct benefit to family.	♦ Easy monitoring and supervision; good link with medical supplies; easy access to professional staff; hospital referral easy.
NGO-based	♦ May not have structural links with formal health care systems; for supplies; may be stigmatised if AIDS specific; sustainability and coverage difficult.	♦ May provide comprehensive support through community volunteers; accessible; may be innovative and flexible.
Faith-based	♦ May moralise and increase stigma; may not be as focused on physical need; may lack the needed skills; eligibility may be restricted to religious affiliation.	♦ Spiritual and social needs addressed; use existing sustainable networks and volunteers; affordable value for prevention and care.
Community based	♦ May be isolated from supplies and hospital back up; may lack technical and supervisory input; difficulty when medical crisis occur; based on volunteer labour of women in the community who are already overburdened.	♦ Use of existing community networks and structures; affordable and acceptable; may contribute to stigma reduction; can address other chronic illnesses
Networks of PLH and those with AIDS	♦ Members may feel abandoned if there is no other support available; ignores other chronic illnesses in need of care; can over extend themselves and get sicker; have to deal with stigma at least in the short term.	♦ Personal understanding; shared experiences and learning; shared burden and can reduce stigma eventually and mobilise prevention actions.
Self-help groups	♦ Isolated from local or national public/private resources; limited/no support from outside.	♦ Grounded in the household and responding to the needs of carers, PLH and those with AIDS and Orphans.

(Adapted from Ogden et al 2004:30)

Each model has its own advantages and disadvantages and therefore there is no perfect model. This reinforces the fact that good aspects of one model could be adapted, modified and incorporated into another model for practicality and enhanced effectiveness.

2.4 PUBLIC HEALTH, DEVELOPMENT AND COMMUNITY AND HOME BASED CARE

2.4.1 Primary health care

The principles of primary health care from Alma Ata in 1987 remain relevant to health care and health service delivery to this day. Although primary health care goals were not achieved in many countries by the set target date of the year 2000, health experts continue to view the principles of universal access, equity, affordability, community participation, empowerment and inter-sectoral collaboration as the foundation of successful health service delivery (Hall & Taylor 2003:17; Lawn, Rohde, Rifkin, Were, Paul & Chopra 2008:919-920). The above principles are developmental in nature.

Community home based care is one strategy of health service delivery that evolved from the concept of primary health care. It affords communities easier access to health care from the readily available and accessible community volunteer health workers. Additionally, support is available from outreach services provided in remote areas by professional health workers in such programmes as immunisation, which is generally widespread. This researcher agrees with the prevailing position taken by health experts that the primary health care concept is still relevant in the current context. This concurrence is based on the existing situation characterised by poverty, and where governments are failing to revamp deteriorating health systems. Chronic illnesses that are emerging and becoming a main area of concern in health service provision have a place in the revitalised Alma Ata (Lawn et al 2008:926).

2.4.2 Community and home based care as a development issue

There is strong relationship between implementing a C&HBC programme and other community development programmes, where the concepts employed for programme

efficiency and effectiveness are similar. These critical components are equity, participation, empowerment and capacity building of programme beneficiaries.

The Alma Ata principle of community participation in primary health care decisions by the public was a noble human development concept that unfortunately did not materialise according to the original programme plans. Lawn et al (2008:924) debate that a lot has been lost in public health by failure to allow communities to own and drive their health priorities and allow links between the health sector and other sectors such as education, environment, agriculture, water and sanitation. This argument appears valid in today's world, where there is an interdependency of various disciplines in promoting health, especially in C&HBC interventions.

2.4.3 Community capacity, empowerment and participation in Community and Home Based Care

The pillars of a successful C&HBC programme, as with any development enterprise, is building capacity within and empowerment of communities to engender participation in initiatives planned and implemented for a specific community. Similarly, without adequate information and knowledge about one's health condition and services provided to alleviate the condition, clients may not know how to access the service. People need to make informed decisions. According to Ratna and Rifkin (2007:519), capacity building enables "local people [to] obtain and act upon new skills and/or knowledge to improve their health." It is an essential step towards empowerment. Empowerment is gained as a result of accurate information and knowledge on a subject. According to White and Harris (2001:129), "it is vital to provide a person with clear and sufficient information to enable them to solve their own problems, which offers them a sense of security in [relation to] future occurrences". The view of this researcher is that in C&HBC, empowerment is also about being able to manage your own chronic illness, or that of a family member, and having the means to do so.

Community participation has often been confused with community mobilisation when in reality it is "an opportunity for community involvement to ensure accountability and transparency in programme implementation" (Ratna & Rifkin 2007:525). Community participation results in a contribution towards meeting wellbeing and health goals (Mapanga & Mapanga 2004:278).

2.4.3.1 Challenges of Community and Home Based Care

Results of a World Bank study (Mohammad & Gikonyo 2005:9) documenting the challenges and limitations of C&HBC in several Sub-Saharan countries, revealed the numerous challenges being faced by C&HBC programmes. These challenges are similar to those faced by the C&HBC programmes in Zimbabwe (Matshalaga 2006:28; Caring from within: ... 2008:41-47; Zimbabwe MoHCW & NAC 2011:46). Some of the challenges recognised that have significance to this study are listed below:

- **Geographical coverage:** C&HBC interventions are concentrated in urban and peri-urban areas, thereby reducing national coverage of the service to only a third of the country, although all districts have some coverage.
- **Poverty and an unstable socio-economic environment:** This has led to a number of inter-related problems that impact on people affected by long-term illnesses. The problems include food insecurity to maintain a healthy diet, reduced means of financing medicines and transportation for hospital follow up visits, and the efficient implementation of the C&HBC programme.
- **The involvement of men** as care givers and volunteers is limited in most areas. The involvement of men in care work has longterm benefits in ensuring healthy families and communities.
- **Service integration:** Weak integration and linkages of the C&HBC activities with other related interventions severely limits effectiveness and efficiency of interventions.
- **Innovation:** Lack of thorough reorientation of C&HBC in responding to the evolving care and support needs of individuals in the programme e.g. those on ART.
- **Human resources:** A shortage of qualified community health workers and managerial personnel to implement programme activities efficiently and provide quality support and supervisory activities. High rates of turnover of care givers and volunteers due to burnout and stress and poor incentives.
- **Training/capacity building:** Insufficient numbers of personnel trained to implement home based care services due to limited financial resources for adequate training and refresher courses of all personnel involved in C&HBC activities.

- **Operational resources:** Inadequacy of resources such as C&HBC kits, telephones/internet access, educational/informational material and the means to transport personnel and/or clients which impedes reaching out to more clients and remote areas.
- **Funding:** CBOs are experiencing challenges in implementation as a result of poor and inconsistent funding mechanism for home based care. Donors are generally withdrawing funding of HBC programmes without any other strategies in place for sustaining the programmes which are still relevant to the community.
- **Coordination and collaboration:** Weak resource and information sharing and cross referrals among all stakeholders involved in C&HBC. This results in lack of standardised procedures and uncoordinated activities.
- **Stigma and discrimination of PLH and those with AIDS:** Renders limited access to those needing care and support and poor disclosure of needs.
- **Weak monitoring and evaluation systems for C&HBC:** Reduces effective tracking of the impact of interventions.

2.5 THE NEEDS AND EXPECTATIONS OF COMMUNITY AND HOME BASED CARE SERVICE USERS

A recent multi-country study (Schoen et al 2009:5-10) examining experiences of chronically ill patients with health service delivery revealed some insightful differences. Dissatisfaction with care was found to be dependent on the organisation and efficiency of service provision and the existing health policies within the respective countries. Among a range of needs and expectations, the other areas of concern raised by patients with complex chronic conditions were: access, coordination, and need for safety, which were linked to unsatisfactory health outcomes. Other studies revealed that clients' rate quality and satisfaction of care based on the behaviour and attitudes of service providers as well as perceived competence (Hasson & Arnetz 2011:1432).

A variety of factors may determine the response clients will have to health care provided. The following section discusses some of the factors that may have a role in influencing the clients' needs and expectations.

2.5.1 Respecting clients belief systems and values

According to Peu (2008:11-17), Lundy and Janes (2009:230-238) and Anderson and McFarlane (2004:114-125), “being able to understand, interpret and accept cultural diversity among people reached by health services, is an essential element to effective, nursing care, participation and communication. Culture can influence C&HBC implementation through beliefs, practices and traditions adhered to by a client and family.” Certain family practices must be respected or negotiated before relevant care can be provided to a client. There has to be a certain level of compromise reached in such situations. The writers further describe certain aspects related to culture which influence care under the theme of “Community Based Transcultural Nursing Care”. Lundy and Janes (2009:230) describes the fundamental aspects of transcultural issues as the following:

- Cultures tend to be stable but may change over time in beliefs, values and cultural lifeways.
- Cultural patterns, norms and practices are powerful influences on human care and transcultural community practices.
- Cultural values and beliefs vary between and within cultures and must be understood to develop cultural congruent practices.
- Cultural rituals, symbols, taboos and practices are important to identify and understand for transcultural nursing.
- Transcultural nursing necessitates studying the total lifeways of people including influences on care related to religion or spiritual, politics, economics technologies, kinships ties, environment and specific values and practices.
- Different modes of communication, use of space, land, property and use of home remedies are all part of discovering the transcultural nursing care needs of people.

The issues above are common in every society, and in line with Imogene King's Conceptual Framework and Theory of Goal Attainment introduced earlier and detailed in a section below, and they clearly reflect the scope of dynamics experienced in C&HBC programmes in general. They may affect learning, interaction and participation of an individual, pair or group. The authors believe that if community home based health

services paid attention to these issues, it is likely that clients' expectations and needs would be addressed amicably. The extent to which transcultural nursing is applied in home based care service provision requires further exploration.

2.5.2 The role and expectations of the family

The role of the family in providing care to a chronically ill family member generates specific and unique challenges for the family members and secondary care givers involved. Care of the chronically ill is generally left to women and girls (primary care givers) who in most instances do not have sufficient knowledge and skill to manage those challenges. (GEMSA 2009:2-3; *Caring from within: ...* 2008:34). The burden of care on women increases stress and reduces their capacity to engage in income-generating activities, which deepens poverty in already vulnerable families.

Family expectations of service provision may differ from those of the client, resulting in conflict and mismatched goals. Adjustments in lifestyle and emotional consequences for family members that may include strained relationships with one another do occur and have to be handled. This study will endeavour to make such observations during the review process, since they may have an effect on needs and goal attainment.

2.5.3 The role and expectations of the health worker and care giver

The role of the professional health worker in C&HBC is to provide care and support according to rules and regulations laid out by health authorities and/or the C&HBC implementing organisations. The secondary care giver, typically a community health volunteer, is also guided by the organisation responsible for their recruitment and training. Both care providers need guidance and direction regarding the service delivery for C&HBC.

Health providers also have their own expectations, which may have an effect on successful service provision and goal attainment. According to a review of home based care activities in Zimbabwe (*Caring from within: ...* 2008:34), community health workers are often overwhelmed with their client's immediate needs to the extent of using their own resources to meet clients' needs. Moreover, secondary care givers often sacrifice their time for engagement in their own livelihood activities in order to meet the physical

and emotional needs of the sick to whom they tend. The consequence of this service provision is burnout, or excessive emotional and physical exhaustion (WHO 2002:42; Gender & Media Southern Africa 2009:3-4) and may have serious consequences for the care provider as well as the client. Barbara Dossey's Theory of Integral Nursing also emphasises the importance and value of self-care among nurses and the importance of regular "self-addressing of stress and emotional pain" (King 2010:224-250). Primary care givers also experience burnout, although it is often overlooked.

The expectations of all care givers are of profound significance to the effective and efficient health service delivery and goal attainment of clients, and need to be taken into account.

2.5.4 The role and expectations of non-governmental organisations in support of Community and Home Based Care programmes

Community and Home Based Care programmes initially require a well thought out strategy and significant input. Governments have relied on Civil Society Organisations including NGOs for the setting up and implementing of C&HBC services. Through donor support, NGOs often fund and provide capacity building to health care providers; cover programme administrative costs, and provide home based care equipment and medical supplies, which are distributed and used by care givers and clients (DSD 2006:38). The organisations also use their administrative and managerial capacity to monitor and evaluate the programmes, in order to assess impact and justify further funding.

Whilst it would be ideal and more practical to see a number of local community based groups initiate home based care programmes to ensure ownership and sustainability, these initiatives would face resource constraints. External donors have a preference for funding organisations that are well established, but often have various other competing needs (Wringe et al 2010:359; Caring from within: ... 2008:47). The authors further argue that a major challenge affecting the delivery of comprehensive home based care programmes is that funding mechanisms that do not always emanate from identified needs of communities and service organisations cannot be sustained locally. Funding therefore has a bearing on the extent to which the needs of a community and clients can be serviced.

2.6 THE THEORETICAL/CONCEPTUAL FRAMEWORK UNDERPINNING THE STUDY

Research literature highlights the importance of incorporating theory into a study. In mixed research, theory is viewed as a lens or perspective that guides a study research from its design to its analysis (Hennink, Hutter & Bailey 2011:37; Creswell 2009:66). In quantitative research, theory is used to provide an explanation of the relationship among variables under study and in qualitative studies, theory provides a broad explanation of peoples' behaviour and attitudes (Creswell 2009:61).

The literature review established several middle range nursing practice theories (King 2010:1-539), some of which are relevant to this study to some extent. Some of the theories are: caring theories and models such as the Community Nursing Practice Model (Parker 2010:451-459) and the Katharine Kolcaba's Comfort Theory (Kolcaba 2010:389-401). These provide important views that relate to the physical, psycho-spiritual, socio-cultural and environmental factors that provide insight on the holistic aspects of health and healing processes. The theory selected to guide this study is Imogene Kings Conceptual System and Theory of Goal Attainment (King 2010:149) described below.

2.6.1 Imogene King's Interacting Systems Framework and Theory of Goal Attainment

The Interacting Systems Framework was developed in the early seventies and later refined into the Theory of Goal Attainment 1981 (King 2010:148). The framework consists of 3 systems, which have an important role in the provision of holistic care and support and ensure effective interaction between patient and health provider. The conceptual framework illustrates three interrelated systems that interact with and between each other and these are: the personal system, the interpersonal system and the social system. The personal consists of perception, self, body image, growth, development, space and time. The interpersonal system consists of interaction, communication, transaction, stress and role. The social system consists of organisation, authority, power, status and decision-making (King 2010:149).

King's Theory of Goal Attainment elaborates upon processes and interactions that ensure the delivery of professional nursing care mainly from the interpersonal system. The theory offers a view that "the goal of nursing is to help persons maintain health or regain health through a systematic process of joint goal setting by the client and the one providing health care" (King 2010:150).

This Framework, and in particular, the Theory of Goal Attainment, were selected to guide this study because all the systems described in the framework are relevant in comprehensive care and support within C&HBC. The elements of interaction between nurse and patient (that are embedded in the theory) are vital for clients' expressed needs and the aspect of mutual goal attainment is the objective of this study. Use of the theory is therefore expected to facilitate the research process and respond to the research questions.

The diagram below shows the elements of the conceptual system that are important for understanding the interactions within and between the systems.

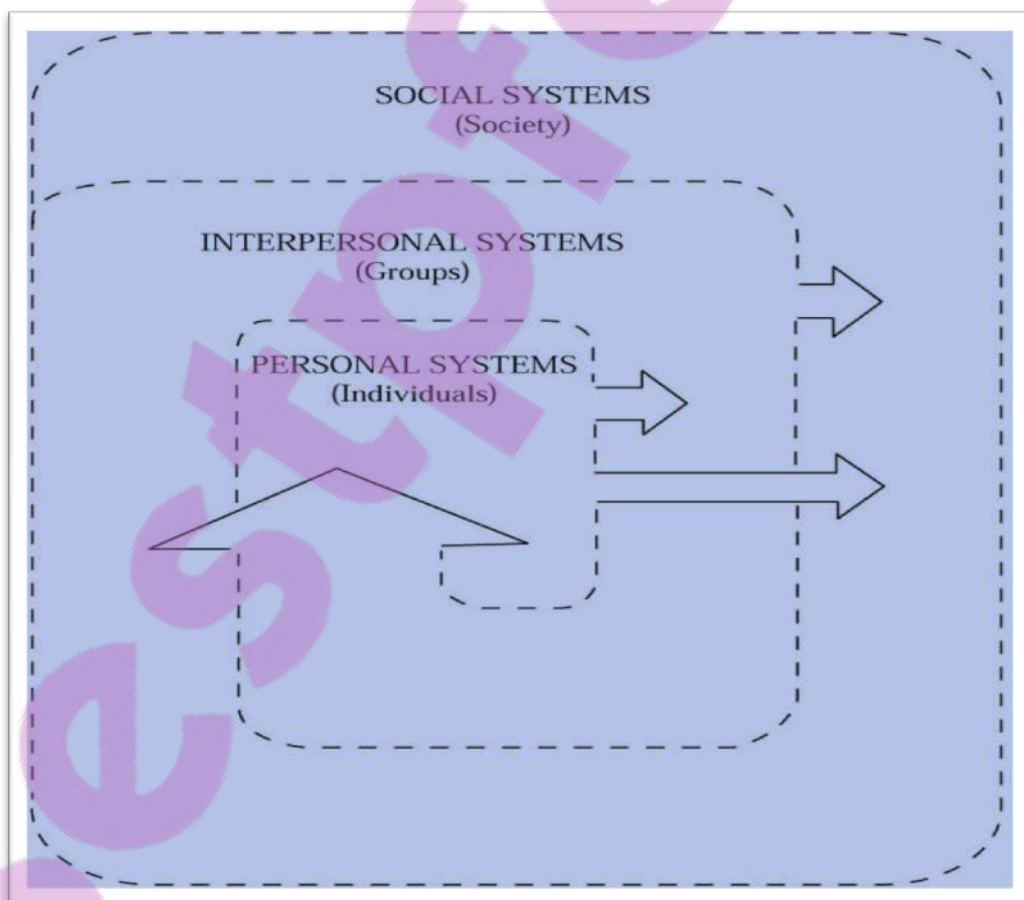


Figure 2.1 Imogene Kings Conceptual System
(King 2010:149 (from King 1981))

In practice, the Theory of Goal Attainment can be applied in various work situations, multidisciplinary fields, within nursing specialties and with clients of various age groups as well as in research to compare interventions and expected outcomes. (King 2010:154-158; Khowaja 2006:49; Goodwin et al 2002:239, Williams 2001:26, Mapanga & Mapanga 2004:276). The assumptions that emerge from these studies are that “goals and interventions must be mutually developed in order to address the rights of clients. The client’s role should be that of active participant” (Goodwin et al 2002:239, 240). Goodwin further asserts that it is important to take into consideration the differences that exist between rural and urban populations when setting goals in order for the goals to have meaning and benefit the client (Williams 2001:28, 29).

Imogene King further developed the **transaction model**, which shows how individuals interact in order to discuss, agree and set goals that are achievable. This model incorporates components of the personal and interpersonal systems of goal attainment, which are: perception, growth, development, time, self, space, interaction, communication, role coping and transaction.

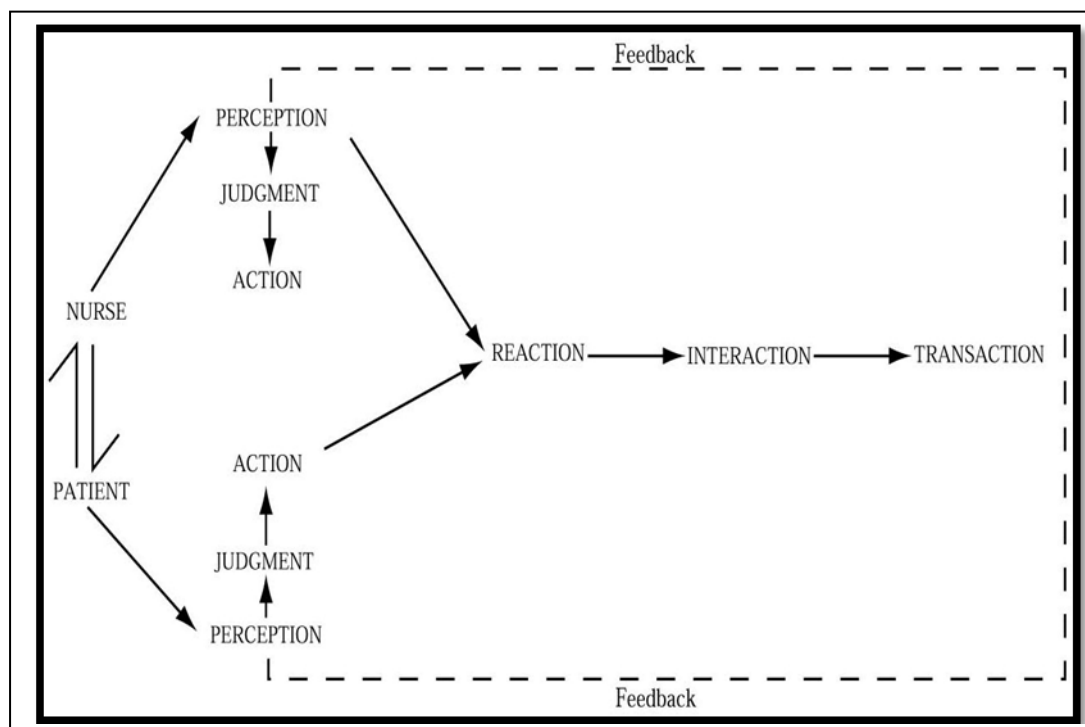


Figure 2.2 The Transaction Process Model

(King 2010:151 (from King 1981))

Transaction is part of the interaction process. When nurse and patient interact, they become involved in dialogue of negotiation and bargaining and feedback until they reach mutual understanding on the nursing goal and means of attaining that goal. Perceptions arise and judgement takes place during the transaction. These have an influence on the decisions made.

2.7 CONCLUSION

This chapter provided a review of literature. It highlighted the strategy and evolution of C&BHC and the core principles that underpin this system of health service delivery. Other sections discussed the review of the following: the strategy and goals of C&BHC; the needs and expectations of C&BHC service users and the community development aspects of public health as it relates to home based health care.

The chapter documented and addressed literature reviewed from the works of various scholars and researchers. It focused on key components of the C&BHC system of health care delivery. These components are the pillars of successful primary health care programmes, which rely mainly upon non-professional health providers with limited expertise.

The literature review reveals that health service delivery is evolving to embrace the escalation of chronic illnesses. This shift means that the health profession has to adjust its strategies in order to meet the complex needs of those with chronic illnesses and the challenges foreseen. The changes will require integration of various services in order to meet these changing health needs.

A community-centred approach to implementing community and home based care might take into account capacity building, which is a pillar of empowerment and community participation. These concepts are not new to health service delivery as they are a part of the primary health care approach. The concepts have not been seriously taken into consideration for ensuring self-reliance for the promotion of health and well being.

The chapter concludes by illustrating the Imogene King's Conceptual Framework and Theory of Goal Attainment, which forms the foundation of this study.

CHAPTER 3

RESEARCH DESIGN AND METHOD

3.1 INTRODUCTION

The purpose of this chapter is to provide a comprehensive description of the research design and the methods used to achieve the purpose and objectives of the study as well as to answer the research questions.

3.2 RESEARCH DESIGN

A mixed-method approach combining qualitative and quantitative data collection and analysis was used. The use of multiple approaches and sources of data/information enabled the triangulation and validation of information for robust and reliable conclusions.

In mixed research or multiple methods research, the investigator uses a combination of both qualitative and quantitative methods of data collection in a single study. A number of authors of research methods (Johnson & Christensen 2012:445; David & Sutton 2007:44; Creswell, Klassen, Plano-Clark & Clegg-Smith 2010:2) have argued that although there is a distinction between qualitative and quantitative research, the two methods share many similarities, and that the combination has “complementary strengths and non-overlapping weaknesses”. Qualitative methods search for meaning from induction, whereas quantitative research is about deduction (numbers and measurements). The understanding is that each method has its own strengths and weaknesses, and each brings out different dimensions of a single phenomenon, and therefore the methods bring about complementarity. David and Sutton (2007:42) assert that the major distinction may be that in quantitative research, there is greater emphasis on reliability and generalisability, whereas qualitative research places emphasis on depth validity which relies on people’s experiences, perceptions, values and beliefs. The qualitative method acknowledges the complex processes and influences in people’s lives and actions.

According to Johnson and Christensen (2012:434), data collection using the two methods may be done with a focus on time orientation, which could be: (a) concurrent i.e. data collection using the two methods is conducted at the same point in time or (b) sequent i.e. data collection is conducted at different times. Another dimension raised by the authors is that of “paradigm emphasis” which considers whether the two approaches/paradigms used have equal weighting or equal emphasis or status without one dominating the other.

This research used a “concurrent collection” of data with equal status placed on both qualitative and quantitative paradigms. This concurrent data collection approach has the advantage of maximising the amount of data collected in the field relative to the time spent, as well as reducing costs while collecting data that is likely to be untainted.

The choice to use mixed methods depends on factors such as the nature of the study, availability of study participants and financial and other resources. According to Johnson and Christensen (2012:34), mixed methods can allow for the study of multiple perspectives, conditions, contexts and factors as they interact. Mixed methods are also expensive and time consuming, as the researcher seeks to solicit views from many sources. However, mixed methods provide complementarity, because the different approaches have different strengths and weakness as stated by Johnson and Christensen (2012:51) and Parahoo (2006:89). The writers echo that by mixing methods, the probability of missing out on important and relevant findings is reduced.

This research employed the mixed method research approach mainly because the research questions sought answers to real-life experiences, multi-level perspectives, including some contextual influences, beliefs and values of the population under study. The investigator also believed that drawing on the strengths of qualitative and quantitative methods would improve the scientific rigour of the study. The use of multiple methods will enhance validity, reliability and generalisability through cross validation of data. According to Johnson and Christensen (2012:439), some of the important concepts of mixed research recommended as best practice in research and adopted for this study, are triangulation and complementarity. The authors, Johnson and Christensen (2012:439), state that: “triangulation provides convergence and corroboration of results from different methods while studying the same phenomenon ...

complimentarity provides elaboration, enhancement, illustration and clarification of results from one method to another. Overlaps and different facets of a phenomenon can thus be understood”.

According to Streubert-Speziale and Carpenter (2007:381), an investigator “can use different types of triangulation in order to provide completeness of the investigation and confirm findings. The types of triangulation strategies are: “(1) data triangulation – use of data collected at different times, data collected from more than one site and data collected from more than one level of respondent; (2) methodological triangulation – using more than one method of data collection; (3) theory triangulation – use of more than one theory in the analysis of the same data; and (4) investigator triangulation – when different investigators with different backgrounds and expertise work together; or (5) a combination of all strategies” (Streubert-Speziale & Carpenter 2007:381).

Johnson and Christensen (2012:36) confirm that mixed research assists the researcher “[in] understand[ing] both the subjective and objective worlds of human beings”. The different approaches used in this study are described in more detail below and their relevance to this study explained.

3.2.1 Evaluative research

According to Round, Marshall and Horton (2008:5) and Zarinpoush (2006:6), there are different types of evaluations, categorised according to the purpose they are intended to serve. In health service delivery, and especially where focus is on client-centred care, evaluative studies offer an opportunity to scrutinise whether the activities implemented result in the intended effects on the population served (outcome evaluation). Evaluation research can be useful in determining the needs of the population and whether or not programme goals were met in accordance with those needs, as exemplified by this study (formative evaluation). Also, evaluations should, in general, aid in providing evidence of successes or failure in order to revisit planned strategies and help to strengthen or improve a programme.

The study used a combination of formative and outcome evaluation approach. The formative approach revealed the needs of clients in C&HBC, whereas the outcome

approach assisted in determining whether or not the clients' needs were met through intervention strategies employed for C&HBC.

According to Parahoo (2006:196), evaluation of programmes is complex and requires the use of mixed methods of data collection to assure that all angles of the programme and stakeholders contribute their views and opinions on the research question.

3.2.2 Qualitative research

A qualitative approach to data collection is claimed to be one of the most reliable research methods in studying health service and its delivery (Parahoo 2006:63). The author suggests that qualitative research has a distinctive feature of exploration, which is necessary in providing in-depth understanding of people's perceptions, emotions, intentions, behaviour and experience. Qualitative research uses interactive, inductive and flexible ways of data collection and analysis (Parahoo 2006:63). As envisaged in this study, the qualitative research aspect will enable exploration of the perceptions of the needs of C&HBC clients and their families, versus care provided by service providers. There may be disparities that are unnoticed or overlooked between needs and service.

The most desired form of "client participation" that is compatible with aims of nursing care occurs through qualitative research. The interactive process of the research methods provides the researched individual or community the opportunity to express themselves freely and to be able to ask pertinent questions related to their health care. Learning or empowerment of the research participant may occur to some extent when their views are listened to, and when they have the opportunity to hear new ideas and concepts, which enable them to reflect further on issues around their illness or situation.

The nature of qualitative data is described by Creswell et al (2010:4) thus:

[Qualitative data] is a systematic and rigorous form of inquiry that uses methods of data collection such as in-depth interviews, ethnographic observation, and review of documents. Qualitative data helps researchers understand processes, especially those that emerge over

time, provide detailed information about setting or context, and emphasise the voices of participants through quotes.

Qualitative research allows for flexibility in sampling and data collection. Although a sample size may exist, an additional sample may be used if there is a need to further explore and build on an issue, and the researcher has been provided with key informants for further exploration of that issue. Also, when data saturation occurs, an investigator can decide to end the data collection before reaching the predetermined sample (Parahoo 2006:66). In this research this method was adopted because it allows for the understanding of health care needs of a target group, which are complex and varied due to the fact that its members experience chronic illness and long-term care. As explained above, qualitative research is “holistic, patient centred and humanistic” (Parahoo 2006:63).

In this study of home based care needs, clients were approached in their own environment and it was therefore easier to relate to their needs and experiences. It was also possible to interview the care givers and other local key informants to provide their own perspectives of the clients’ experiences and needs, thus providing multi-level perspectives of the issue under study.

3.2.2.1 Sampling for the qualitative approach

In purposive sampling, participants selected are those who are available to provide data on the issue being researched (Parahoo 2006:268). The researcher specifies the characteristics of a population of interest and intentionally locates them. Purposive sampling can be used in both qualitative and quantitative research (Johnson & Christensen 2012:231). The choice is determined by the research question and whether the target is the most suitable in answering the research question. There are limitations to the study that include the lack of ability to generalise findings of the sample to the larger population in purposive sampling.

This study utilised purposive sampling through the involvement of non-governmental organisations implementing C&HBC in the urban and rural areas of Harare City and Marondera District, respectively. The organisations operate in selected wards (the lowest local authority administrative unit in a district) and municipal areas with similar

needs for the service. The choice of a purposive sampling strategy was also influenced by restricted access to potential participants/clients on home based care for chronic illnesses. Access to the clients required the consent of those directly involved in their care and support. Another factor was the substantial human, financial, material resources and time required to access the clients at home or nearer their homes.

Authors of research methods and design (Parahoo 2006:274; Johnson & Christensen 2012:231) state that although sampling is usually decided upon at the beginning of a study, it is possible to increase the sample size if more data is required, or to discontinue data collection if no new ideas that add value to the study are emerging, and a point of saturation is reached.

3.2.3 Quantitative research

Compared to qualitative research, quantitative research may also be viewed as exploratory. It functions this way through measurement of variables and statistical analysis. Quantitative methods can be limiting in exploring and explaining reasons why a particular phenomenon occurs. David and Sutton (2007:42), however, refute that statistical analysis is impossible in qualitative research. The authors claim that measurement can occur in quantitative studies, such as measuring whether certain qualities observed are greater or lesser between sampled individuals or when assessing different spending patterns between respondents.

The nature of quantitative data is described by Creswell et al (2010:4) in clear terms as follows:

[Quantitative research] is a mode of inquiry used often for deductive research, when the goal is to test theories or hypotheses, gather descriptive information, or examine relationships among variables. These variables are measured and yield numeric data that can be analysed statistically. Quantitative data have the potential to provide measurable evidence, to help to establish (probable) cause and effect ... to create the possibility of replication and generalisation to a population, to facilitate the comparison of groups, and to provide insight into a breadth of experiences.

3.2.3.1 Sampling for the quantitative approach

Purposive sampling was also used for the quantitative aspect of this study. The same clients and care givers sampled for the qualitative component participated in the quantitative survey. David and Sutton (2007:151) suggest that whilst probability sampling is preferred when non-probability sampling is used, generalisability of findings to the population becomes difficult.

According to Parahoo (2006:256), sampling involves deciding the number and characteristics of respondents who will participate in the study. A study requires a sample (a proportion or subset of a target population) that will be representative of the whole population in the locality under study, and one that can result in the generalisation of findings and conclusions to similar settings and populations.

3.3 RESEARCH METHOD

3.3.1 Sampling

3.3.1.1 The population

The study population consisted of the following:

Primary population: Chronically ill persons enrolled in a formal C&HBC programme. Primary care givers will be enrolled in the study.

Secondary population: Stakeholders, namely, health institution managers, non-governmental organisations implementing home based care programmes, Ministry of Health and Child Welfare authorities, community health workers and community/local leaders.

The sample was from the rural and urban settings of Mashonaland East Province and the urban setting of Harare Metropolitan Province. Samples were identified and taken from one rural district in Mashonaland East Province (Marondera District), four residential suburbs in Harare, and one in Marondera town. Harare is a Metropolitan Province and the district of Marondera in Mashonaland East Province comprises an

urban and a rural area. The provincial settings were selected because of their representativeness, in terms of the comprehensive coverage of home based care programming, and geographic accessibility. The sample of the research settings is representative for the purpose of the study objectives in that it covers a variety of both urban and rural populations; the areas represent a range of different contexts of chronic home based health care delivery in the country, which provide a broader exploration of the needs of patients with long-term illnesses. The specific areas and suburbs covered by the study and the sample are outlined in table 3.1.

3.3.1.2 Sampling and sampling procedure

This research was carried out in February and March 2012, for a period of three and a half weeks. The qualitative and quantitative research was carried out at the same time and some of the respondents participated in both the quantitative and qualitative aspects of the study. This, according to Johnson and Christensen (2012:238), is called “an identical concurrent sample relation criterion”.

The research used a criterion-based/purposive sampling approach (Johnson & Christensen 2012:235). The sample was drawn among available and consenting members of the community who had experiences of home based care for chronic illness. The views of those who were not involved in home based care were solicited from community leaders and community volunteers involved in other community based programmes. Maximum variation sampling was used, which is described by Johnson and Christensen (2012:236) as purposively selecting a wide range of cases from rural and urban settings. Participant selection and recruitment also included those at home, and those who were able to meet the research team at a community meeting place nearer to the clients’ homes. This method ensured that the views of all types of cases with diverse experiences of care were heard.

Sixty-one (61) quantitative survey participants were drawn from primary care givers, who are relatives, family and friends of the clients under study, as well as 145 C&HBC programme clients. In total, 206 participants were enrolled in the quantitative survey.

Key informants (KIs) included community leaders, senior managers and personnel at health institutions and other stakeholders. At each study site, at least one focus group

discussion was conducted with community health workers, primary care givers, community members and ambulant clients enrolled in the C&HBC. A total of 12 focus group discussions were held with 110 participants. A total of 34 key informant interviews were conducted.

3.3.1.2.1 Inclusion criteria

Primary participants

- Persons with a chronic illness
- Individual adults between 18-60 years of age with the ability to comprehend and respond to questions (the legal age of consent in Zimbabwe is 18 years)
- Individuals enrolled in a C&HBC programme
- Family care givers of chronically ill clients
- Individuals who are able to provide informed consent

Secondary participants

These were health service providers, community health workers, stakeholders, and key informants directly involved in the management and implementation of community and home based care programmes. Involvement implies active participation in decision-making, programme design, implementation, management, and facilitation of care and support.

3.3.1.2.2 Exclusion criteria

- Poor mental status resulting in inability to provide comprehensive responses
- Seriously ill persons: defined as being unable to communicate, being assisted and unable to carry out activities of daily living

The selection criterion was developed to exclude only those who were minors and those who were seriously ill and unable to respond to questions. The rationale for excluding the young was based on the assumption that not many children experience chronic illnesses in the country. However, care givers of young children were included in the

study to provide perspectives from children's care needs. The approach used to follow up bedridden clients in home and institutions of care, allowed for wider inclusion of those with chronic illnesses and those under care. Rural communities as well as urban dwellers were provided with equal chances to participate and share their experiences, perceptions and needs.

Table 3.1 Description of study coverage and sample

Province	Area	KI sample	FGD sample	Survey sample		Data collection method
				Service users	Primary care givers	
Harare Urban	Mabvuku High Density Area, Harare	3	8	10	6	Focus Group Discussion and Structured Questionnaire
	Kuwadzana Ward 37 Harare	4	6	20	5	Focus Group Discussion and Structured Questionnaire
	Mbare High Density Area	5	11	22	5	Focus Group Discussion and Structured Questionnaire
	Tafara High Density Area (Urban)	0	18	10	12	Focus Group Discussion and Structured Questionnaire
	Dzivarasekwa H/Density Area (Urban)	2	26	19	14	Focus Group Discussion and Structured Questionnaire
	Harare Urban	3	-	-	-	In-depth Interviews
Marondera District	Marondera/ Rusike High Density Area	3	10	15	4	Focus Group Discussion and Structured Questionnaire
	Wenimbi East- Ward 6 Marondera Rural District	5	16	29	8	Focus Group Discussion and Structured Questionnaire
	Garikayi- Ward 10 Marondera	3	8	16	7	Focus Group Discussion and Structured Questionnaire
	Ruwari Resettlement-rural Ward 23	1	0	4	0	Structured Questionnaire
	Marondera Rural and Urban	5	-	-	-	In-depth Interviews
TOTAL		34	110	145	61	Mixed Methods

The limitation in achieving a large sample was a result of unanticipated community events that occurred at the same time as the study. These included funerals; political meetings; food aid programmes and Opportunistic Infection/Antiretroviral Therapy (OI/ART) scheduled and re-scheduled clinic visits, which attracted the same participants as those that were required for this study. The majority of clients on C&HBC have AIDS-related chronic ailments such as cancer, neuropathy and other conditions which result in them seeking social assistance and frequent health care and treatment. Since the introduction and concerted efforts by the Ministry of Health and Child Welfare to increase access to ART in both rural and urban areas, the majority of clients who were once bedridden as a result of opportunistic illnesses, are now healthy and ambulant and therefore not always available where they reside. These developments affected the researcher's access to respondents, especially primary care givers, who were often absent from homes and meeting venues as they pursued their personal interests and livelihoods.

The final sample size of 206 responses for the quantitative survey did not meet the intended target set in the project proposal. A total sample size of 300 care givers and clients had been found adequate at 95% confidence level, and a 20% margin of error for both the urban and the rural population. Although the target was not met, the sample size attained is adequate to provide statistically significant results to make accurate inferences. A larger sample size would be preferred, since it would improve the confidence level. In discussing the structure, process and content of qualitative and quantitative interviews, Parahoo (2006:325) and Johnson and Christensen (2012:239) note that while quantitative methods of data collection are characterised by mathematical modelling, consistency and standardisation, a qualitative approach is more flexible in sample size and generation of data. The flexibility is reflected in the recognition of "data saturation" which can occur when no new insights, views or relevant data are generated from further interviews with different respondents. The authors state that when no new data emerges, the researcher can stop further interviews. As data collection progressed for this study, there was also realisation that no new relevant data was emerging from site to site. A robust analysis is expected to yield valid findings from the sample size used.

3.3.2 Data collection

3.3.2.1 *Data collection approach and method*

The survey utilised a multi-method approach, incorporating both qualitative and quantitative tools and methods of data collection to enable cross-validation of data. Methods included in-depth face to face interviews with policy makers, programme planners, programme implementers and community workers/leaders as key informants. Structured interviews were held with clients and their primary care givers. Focus group discussions were also conducted with ambulant clients and their primary care givers at community level.

The study design required a rural and urban population, for comparison of C&HBC needs between populations. Harare Central and Marondera districts were chosen due to their ease of access to the researcher. The two areas have Non-Governmental Organisations implementing C&HBC programmes. These were partnered in the research, allowing easy and lawful access to the community, clients, stakeholders and government departments. FACT Rusape is the sole organisation implementing C&HBC in Marondera District, and Mashambanzou Care Trust is the pioneer and main implementer of C&HBC activities in Harare, with a strong presence in many parts of Harare Central district. These organisations became the affiliate or partner organisations in this study.

Permission for entry into the community of Marondera district was granted by the Provincial Medical Directorate/Ministry of Health and Child Welfare and the Ministry of Home Affairs. The City Health Department of Harare Municipality granted permission for key informant interviews at the city health care facilities.

In Harare Metropolitan area and Marondera district, sampling remained purposive. The affiliate organisations provide C&HBC services in specific “Wards/Geographic Sections” as stipulated in their operational plans. These areas were taken as the study sites. As shown in the sampling table above, five suburbs in Harare and four wards in Marondera district were sampled for the study. Participants were recruited within their community settings through the assistance of volunteer care givers, who hold registers of

chronically ill people in the villages. Ambulant clients were escorted by their care givers and interviewed at community meeting points near their homes. The research team conducted home visits to recruit and interview bedridden clients in each area. Recruitment into the study was based on the study selection criteria.

At recruitment, the objectives of the study were explained to potential participants and all relevant information about the study read out from the designed information sheet. Individuals volunteering to participate in the study were requested to sign a consent form. The participant retained a copy of the signed form. An opportunity for participants to ask questions was provided following an interview.

Key informants within the community were recruited, based on their availability, awareness of and involvement in C&HBC and other community service activities. Senior health facility personnel who served as key informants were recruited from the only health facility serving the rural study sites in Marondera District, and from four municipality clinics within the Harare study sites.

3.3.2.2 Development and testing of data collection instruments

A variety of tools were developed and used to collect data and information from the different sources mentioned above following pretesting. These tools ranged from FGD question guides, structured house hold questionnaires and KI Interview guides designed for specific categories of key informants.

3.3.2.2.1 Validity and reliability

According to Parahoo (2006:283-312), if information gathered is to be useful to policy makers and practitioners, the instrument should produce reliable and valid data. The validity and reliability of the questionnaires/tools for data collection is critical in any study. Validity of the tool is determined by the extent to which it addresses the research questions and objectives of the study. The reliability will be determined by the consistency with which respondents understand and respond to all questions (Parahoo 2006:300).

Data collection tools for both the qualitative and quantitative methods were pre-tested for a day in the Harare metropolitan area in order to establish consistency, validity and reliability, and to guide appropriate adjustments of the tools.

Following the pilot study, the tools were revised in the light of experiences from the pre-testing and finalised for use in the field. Standardisation of practice, process and approach was also established before fieldwork was carried out. At the end of each field day, the team met to review the data collected. The end of day reviews enabled anomalies to be noted and corrected so that problems were rectified at the earliest opportunity. Questionnaires were checked for accuracy, completeness and consistency during these review sessions.

A potential challenge identified during pilot testing was the difficulty encountered in linking each client to a primary care giver. This challenge resulted from clients who did not require primary care givers, because they were no longer bedridden. As a result, interviews with family care givers were conducted only with those care givers available (in the actual study), who numbered fewer than the clients in total. Nonetheless, the data gathered from those respondents provided reliable information on care-needs from the care givers' perspective. The identification of this challenge during pretesting therefore assisted in making adjustments to the site data collection protocol, to ensure a clear and realistic data collection process.

3.3.2.3 *Characteristics of the data collection instruments*

The tools and methods for data gathering were developed separately for the qualitative and quantitative data collection. For the qualitative methods, question guides and focus group discussions were used. A structured questionnaire was used for the quantitative survey. The structured questionnaire comprised open-ended and closed-ended questions. The closed questions had specific categories of responses from which participants were able to select. The categories were generated from the literature review of this study and from the researcher's knowledge of some of the indicators for measuring quality health care in the delivery of C&HBC. Open-ended questions enabled the respondent to provide their own responses and also to expand on responses in the categorised sections.

3.3.2.4 The data collection process

3.3.2.4.1 Focus group discussions with clients and primary care givers

This group of respondents was mobilised within their communities and discussions were held with the researcher at designated community meeting points. The participants consisted of persons who at the time the study was conducted, were directly or indirectly involved in the C&HBC programme i.e. clients, community and primary care givers and community members with experience of chronic illness.

The FGD guide solicited information on the respondents' perspectives of the C&HBC programmes and the needs and expectations of the chronically ill in the targeted area communities. The discussions also sought information about community participation and empowerment, and suggestions regarding a future sustainable C&HBC programme. The objectives of the discussion were as follows:

- To enable participants to dialogue about the needs and expectations of clients on home based care and current care practices.
- To probe such issues as community participation and decision-making, and other health-seeking related behaviour in relation to C&HBC.
- To elicit perceptions on the main successes and challenges of the programme.
- To verify data obtained at other sites.
- To record views on what clients' needs should be met as well the role of the community/family in meeting these needs.

3.3.2.4.2 Key informant interviews (Level 1)

KIs were conducted with local leaders, community health workers and individuals knowledgeable about the C&CHB programme. As above, the FGD guide solicited information with the following objectives:

- To provide qualitative data to complement/triangulate that collected by other methods and from other sources.

- To determine what needs of chronically ill clients are being met or not met and for those not met, to find out the reasons why?
- To determine whether there is a clear strategy for community participation and decision-making in the design, implementation and evaluation of C&HBC services? To determine whether local beneficiaries of C&HBC are consulted and adequately involved?
- To identify the successes, and major gaps in service provision and in implementation. To also identify the challenges and opportunities that exist in C&HBC for future programmes.

3.3.2.4.3 Key informant interviews (Level 2)

These were conducted with service providers within Government Departments at Local/District and National Levels and from organisations implementing C&HBC. In this category senior officials at health facilities and the MOH&CW served as key informants and also as sources of data/information triangulation. The FGD guide solicited information with the following objective:

- To provide qualitative data to complement/triangulate that which was collected by other methods and from other sources.
- To elicit information on perceptions regarding the health care decisions in setting goals and service delivery for C&HBC and congruency of goals with the needs of service users.
- To determine whether or not the programme is succeeding in meeting client's goals and objectives.
- To identify the successes, and major gaps in service provision and in implementation. To also identify the challenges and opportunities that exist in C&HBC for future programmes.
- To determine whether there is a clear strategy for community participation and decision-making in the design, implementation and evaluation of C&HBC services; and to determine whether local beneficiaries of C&HBC are consulted and adequately involved.

3.3.2.4.4 Structured questionnaire for clients and primary care givers

The survey was conducted through interviews carried out with the help of research assistants. The questionnaire consisted of a combination of different types of formats, which included open-ended questions, closed-ended questions, rating scales, and listing. The questions solicited information with the following objectives:

- To obtain background demographic information on the clients and care givers. This information is vital for the classification of respondents as well as for comparison.
- To gauge the needs and expectations of individuals/clients on home based care as well as that of family and community care givers.
- To assess the extent to which clients' needs and goals are met through the programme.
- To obtain views on what clients' needs are to be met and how they might be met; as well as on the role of the community/family in meeting these needs.
- To gain interviewees' perceptions on the programmes successes, challenges and opportunities around community and home based care.
- To probe participants' level of involvement/participation in programme design and implementation.

Data gathered was analysed using appropriate software for both qualitative and quantitative data. The qualitative and quantitative data was further triangulated to determine consistency and reliability.

3.3.2.5 Study ethical considerations

3.3.2.5.1 Permission to conduct research

Authors of research design and methods (Parahoo 2006:111; Bless, Higson-Smith Kagee 2006:141; Streubert-Speziale & Carpenter 2007:62) suggest that there are important ethical issues which researchers should be concerned with during all stages of a research process. Researchers are morally obliged to observe certain ethics, in order to generally safeguard patients' rights. In nursing science and practice, the

principles of “always doing good” (beneficence) and “doing no harm” (non maleficence) to patients is the foundation of effective health service provision. Other fundamental principles, such as confidentiality (protection of information), autonomy (freedom and choice) and justice (fair treatment and equality), are of essential in preserving peoples’ dignity and respect (Bless et al 2006:142, 143). These principles apply to both qualitative and quantitative studies. In both methods, there is bound to be anxiety, distress and a feeling of exploitation from the interviewee (Parahoo 2006:113).

Research Ethics Committees were set up to assess the ethical implications of studies which can otherwise be unknowingly detrimental to the lives of research participants. The code of ethics and its guidelines are concerned with the protection of human rights violations in research involving human subjects. (Parahoo 2006:112; Griffiths 2009:4; Streubert-Speziale & Carpenter 2007:61). For this study, the University of South Africa (UNISA) Research Ethics Committee reviewed the study proposal and granted clearance for the research. A similar body, the Medical Research Council of Zimbabwe (MRCZ), also reviewed the proposal as is statutory requirement, and approved its compliance with ethical standards for human research. Prior to clearance from the MRCZ, the researcher sought permission and approval with affiliate organisations with direct contact and ongoing relationships with the communities they serve in home based care programmes.

3.3.2.5.2 Voluntary participation (autonomy)

People should enjoy the choice of whether or not to participate in a study. Any form of coercion should be avoided. Where payment or other incentives are offered, there should be strict procedures ensuring that participation is by individuals who qualify according to the study protocol. In all cases, participation should be voluntary. If participation is confined to a particular group of people this may reduce generalisability of findings.

Voluntary participation is linked to disclosure of adequate factual information to potential participants on details of the study, including the risks and benefits. It is expected that people are able to make informed decisions regarding their participation when sufficient information has been provided to them.

To ensure autonomy in this study, a written statement explaining the purpose of the study and procedure for data collection was developed. This was done to ensure consistency in information provided to all potential participants. They were informed of the purpose of the study and its implications to their continued care in the C&HBC programme. Participants were given a choice to either participate in the study or to decline.

3.3.2.5.3 Informed consent

When equipped with sufficient information, potential participants should be requested to provide signed consent for participation. Johnson and Christensen (2012:107) defines informed consent as “agreeing to participate in a study after being informed of its purpose, procedure, risks, benefit, alternative procedures and limits of confidentiality”. According to Streubert-Speziale and Carpenter (2007:63), informed consent is also grounded on the ethical principle of autonomy in that “it encompasses the notion of being a self governing person with decision-making capacity”.

The consent form for this study contained aspects presented in the definition of informed consent described above, and those that are relevant to the study including: knowledge of the questions that will be asked in the interview; participation being voluntary; and the participant’s capability to withdraw from the study at any time during the study.

It might be difficult to convince participants that withdrawal will not have adverse effects on their health care, but this should nevertheless be done. To avoid participants feeling that refusal to join the study or withdrawal from the study may jeopardise their chances for future treatment and care, a clause was included in this study to point out that this would not be the case.

Participants who volunteered to participate in the study provided written informed consent. Consent forms were translated into Shona (the local language), for those participants unable to read in English. Study information and consent forms were read out to those unable to read. It was stressed and reiterated to all participants that their decision to participate in the survey was categorically voluntary.

3.3.2.5.4 Confidentiality (non-maleficence)

This requirement of respecting peoples' privacy applies to all nursing practice, and is critical in conducting ethical research. It is the basis of appropriate interaction with human beings. According to Johnson and Christensen (2012:116), "confidentiality is not revealing the identity of the participant to anyone other than the researcher and his or her staff". Data collected should be shared only with other researchers and should be kept anonymous where identification is not required for further follow up research. Separating documents such as consent forms with participants' names from the completed questionnaire is one way of ensuring confidentiality as was practised in this study.

Confidentiality and the protection from invasion of privacy were prioritised throughout the study. The interview sessions were carried out in secluded settings to ensure privacy and confidentiality. Emphasis was placed on information being shared between interviewee and interviewer in privacy and confidence. Participant's names were not used on the data collection forms for the survey and during focus group discussions. Numbers were assigned to data collection forms for identification. However, names and organisations of key informants were recorded for the purposes of follow up, if necessary. All forms with information about the participants are stored separately from the completed questionnaires and in secure storage.

3.3.3 Data processing and analysis

Data collected during the evaluation was verified for completeness and accuracy during the fieldwork and during the data cleaning exercise after the completion of field work. Data collected through the structured questionnaire (quantitative data) was collated and entered into a CSPro data entry template, before being exported to excel and Statistical Package for Social Sciences (SPSS) for analysis. A code book was developed to enter themes and categories for the management of the coding system, using latent and manifest codes. 'Manifest codes' are terms that recur within the data collected, whereas 'latent codes' are those themes that are implied in the text and are identified by the researcher (David & Suttonl 2007:204). The code book for this study lists all the codes generated and applied to the data for establishing of patterns and themes. The quantitative questions were pre-coded before data collection and analysis.

Quantitative data analysis is presented as descriptive statistics, showing frequencies, and cross tabulations. As part of data analysis, comparisons are made to search for patterns, themes and trends between the various groups sampled from various settings.

For the qualitative data (FGD and key informant interviews), specific data entry templates were developed for the purpose of entry and analysis in NVivo. Data was synthesised and analysed by thematic areas. NVivo analyses detailed textual and/or multimedia data. The software removes manual tasks, such as classifying, sorting and arranging information. The NVivo analysis tool/software helps to clarify understanding of study data; discovers meaning and patterns; and identifies themes to arrive at answers to the research question and to devise conclusions about the research findings. Qualitative data is presented using thematic formats such as tables.

3.4 INTERNAL AND EXTERNAL VALIDITY OF THE STUDY

According to Parahoo (2006:80), “the study finding must be credible in the final analysis; and for credibility to occur the data collected should be rigorously checked for accuracy, compared with other participants and key informants responses and rejected if necessary until there is overwhelming evidence of indisputable information”. Validity is about the correctness and truthfulness of the inferences that are made from the study (Johnson & Christensen 2012:245). Validity is broadly measured in two dimensions, those of **internal and external validity**.

3.4.1 Internal validity

According to Johnson and Christensen (2012:247), “internal validity is simply referred to as causal validity because it is about establishing trustworthy evidence about cause and effect”. Internal validity is about exploring the cause and effect relationship of a phenomenon under study. This applies to quantitative research. It is concerned with whether the study has taken into consideration all other factors, which may affect the changes that have been noted in a population or individuals. According to Johnson and Christensen (2012:268), quantitative researchers are more concerned about cause and effects than are qualitative researchers.

This study improved the internal validity of the qualitative method by data triangulation and triangulation through use of other methods (methods triangulation) of data collection. Methods triangulation involves using more than one method of data collection, whereas data triangulation relies on multiple data sources (Johnson & Christensen 2012:269). The authors claim that these strategies improve internal validity of qualitative research and that such strategies have also been used in this study.

3.4.2 External validity

Johnson and Christensen (2012:256) define external validity as “the extent to which the study results can be generalised to and across populations of persons, settings, times, outcomes and treatments variations”. From the authors’ definition, it is difficult to generalise individual study findings since they all tend to have characteristics that threaten external validity.

According to Bless et al (2006:93), in order to achieve high external validity, the sample must be large enough to be representative of that community, and the study must be as close as possible to the situational reality of that community or population. The study should avoid disturbing the status quo of the participants, so that they do not become anxious and reactive, as this could lead to simulated behaviour and information. These authors claim that it is uncommon for a study to encompass both high internal and external validity. Each study will have more of one of these types of validity than the other, due to effects of complex community dynamics on research variables. Efforts to ensure external validity were made through the use of mixed methods and sources of data collection, to ensure triangulation of information. The sample size was sufficient as it lead to data saturation, thus increasing external validity.

3.4.3 Reliability

Reliability is the consistency or stability of the test score or measurement tool. Johnson and Christensen (2012:138) further claim that if an assessment produces reliable scores, the scores will be similar on every occasion. Parahoo (2006:79) also adds that “reliability in quantitative terms is the consistency with which the data collection tool measures what it is supposed to measure”. A reliable tool should be able to produce the same results if used in a different set up or group on every occasion that it is used.

Pretesting of the qualitative tools and quantitative tool was carried out to ensure reliability of the instruments. Reliability can be improved by pretesting the research tool or instrument through piloting the questions, or through the use of questions that have been used previously in other rigorous professionally conducted studies (Parahoo 2006:79). The pilot testing was done on a small group similar in characteristics to the intended respondents. The test was used to gauge whether respondents understood the questions; determined understanding of the language/words by participants; determined the length of the questionnaire, and how relevant the questions were, among other issues that served to strengthen the value of the tool after review.

According to Parahoo (2006:79), “reliability in quantitative terms means consistency of measure and is rejected in qualitative research since the interaction of a researcher and participant is a unique encounter, which may not be replicated in many or all situations”.

The interactive encounter between researcher and interviewee is viewed as an enriching in-depth experience necessary for useful information in health programming. The argument for inconsistency is based on the belief that research participants can provide responses that they think are acceptable, rather than telling the truth when questioned directly. However, this can apply in both qualitative and quantitative data collection. Awareness of this challenge prompted the researcher to probe further and triangulate data whenever inconsistencies were observed during interviews.

Since qualitative exploratory interviews are generally considered to have greater validity due to in-depth discussions with respondents, this approach enhanced reliability in this study. The researcher endeavoured to be as objective as possible in data interpretation of qualitative data, through using qualitative data software NVivo for analysis to avoid subjectivity and increase reliability.

In order to balance reliability and validity in this study, the structured questionnaire was designed to contain a mixture of methods to measure variables and different questioning techniques to overcome some of the challenges of lack of reliability and validity of both the tool and the findings.

3.5 TRUSTWORTHINESS

The use of concepts for describing trustworthiness differs between the qualitative and the quantitative research methods. In qualitative research, trustworthiness is established when findings closely reflect the meanings of the phenomenon under study as described by the participants (Lietz, Langer & Furman 2006:444). The nature of this mixed method study required the researcher to represent, as closely as possible, the perceptions and experiences of clients with chronic illnesses. Attention to this detail is part of upholding the ethical responsibility required in research. In that regard attentiveness to the issues of trustworthiness which require adherence to the concepts of credibility, dependability, transferability and confirmability was considered throughout the research, that is, from design, sampling, data collection and analysis. According to Shenton (2004:64) the above terms which reflect validity and reliability in quantitative research are preferable in qualitative research. "Credibility is preferred to internal validity; dependability preferred to reliability, transferability to external validity/generalisability and confirmability to objectivity".

Plausible study finding and conclusions should aim at reflecting trustworthiness. The following list shows how threats to trustworthiness were managed in this study:

- Sampling decision – the sample of study participants was taken from individuals who had experienced chronic illnesses and relatives directly affected by the chronic condition. This strategy ensured effective attainment of the research goal and objectives and a reflection of true experiences of the subjects under study.
- The sample size was considered adequate to generate sufficient data for valid conclusions and generalisation to similar populations and settings.
- Use of research assistants in the collection of data and meetings to discuss and confirm findings each day following field work reduced the researcher's bias and reliance on own perceptions. This peer debriefing also ensured triangulation of findings between the researchers.
- The same group of study participants was used for both the qualitative and quantitative aspects of the study. This increased the credibility of data obtained from both sources and ensured greater triangulation.
- Triangulation was established in this study through the use of different data collection methods such as indepth interviews and focus group discussion, as

well as through the structured interviews used to collect quantitative data. The use of a wide range of informants from various organisations and institutions also promoted triangulation.

- The use of qualitative data software, Nvivo, for data management and its analysis authenticates findings and increase the integrity of findings and conclusions (Sinkovics, Penz & Ghauri 2008:694).

The above strategies were employed to ensure rigor and strengthened the findings of the study.

3.6 CONCLUSION

This chapter provided a description of the study design and methods used to achieve the study purpose and respond to the research questions put forward. The study used mixed methods of data collection, collating, analysis and interpretation of findings.

Qualitative data was generated through structured interviews and focus groups, with C&HBC clients, their primary care givers and volunteer community health provider including programme implementers and medical/nursing personnel from various health facilities and organisations.

Quantitative data was gathered through structured interviews with clients of C&HBC and their primary care givers. This provided first hand insight into the needs and expectations of people suffering from long-term chronic illnesses.

Purposive sampling of respondents for both qualitative and quantitative methods was applied in order to target a sample, with specific characteristics required for achieving the study objectives, and to ensure comparison of findings for greater validity.

The chapter further discussed the data collection process; the critical ethical issues observed in data collection and its analysis. A discussion also centred on how the study will guarantee reliability, validity and trustworthiness considering the challenges of a mixed method study design.

CHAPTER 4

DATA ANALYSIS AND PRESENTATION OF FINDINGS

4.1 INTRODUCTION

This chapter presents the analysis of data and findings from the research. Quantitative data was obtained from two sets of respondents, namely service users of home based care programmes, and their primary care givers. Qualitative data was generated from focus group discussions with service users and primary care givers and from in-depth interviews with key informants, from policy makers, programme implementers and community representatives. In some instances, the data will be stratified according to whether it was obtained in urban or rural settings. The chapter begins with the description of the analytical process which includes data cleaning, coding, organisation and reduction. Research findings are presented in thematic areas or categories. These were generated through coding of participants' responses from qualitative data, and are useful in representing an array of issues raised in responding to the research question (Creswell 2009:189). The chapter will also discuss the characteristics of the sample under study; the results of the data analysed from the structured questionnaires; the face to face interviews, and focus group discussions.

A comparison of the results obtained from rural and urban settings will be made. Comparison will also be made of qualitative and quantitative data. The rural and urban comparisons will provide greater insight into the study objectives. Qualitative and quantitative data collected for this study will be analysed separately before comparison. According to Creswell (2009:220), comparison of qualitative and quantitative data in a mixed concurrent study such as this one can be presented separately. The author further indicates that the two should be combined at data analysis and interpretation stages to determine "similarities and convergence".

The purpose of this study was described in chapter 1, as being to achieve the following:

- To explore whether C&HBC provides services that effectively meet users' goals in an ever-changing social environment.
- Utilise the findings of the study to develop a protocol for harmonising the service users' needs and expectations with the health delivery system to attain specific goals and objectives.

In order to meet the purposes of the study, the data collection and analysis was guided by the following three research questions and four objectives:

Research questions

- How does the current delivery of C&HBC meet service users' needs and expectations?
- What is the extent of community participation and decision-making that guarantees attainment of service users' needs and goals, as well as expected health outcomes (the secondary goal of social development)?
- What are the key areas of need that have been identified to develop a guideline for harmonising service users' needs and expectations with the health delivery system for goal attainment?

Research objectives

- To explore and describe the health care needs and experiences of chronically ill service users enrolled in a C&HBC programme.
- To determine whether the C&HBC programme interventions are meeting the intricate goals of chronically ill service users in an ever-dynamic environment.
- To determine the congruency of service users' needs and expectations and the health delivery system goals.
- To use the findings of the study to develop guidelines for harmonising C&HBC service users' needs and expectations with the health delivery system for goal attainment.

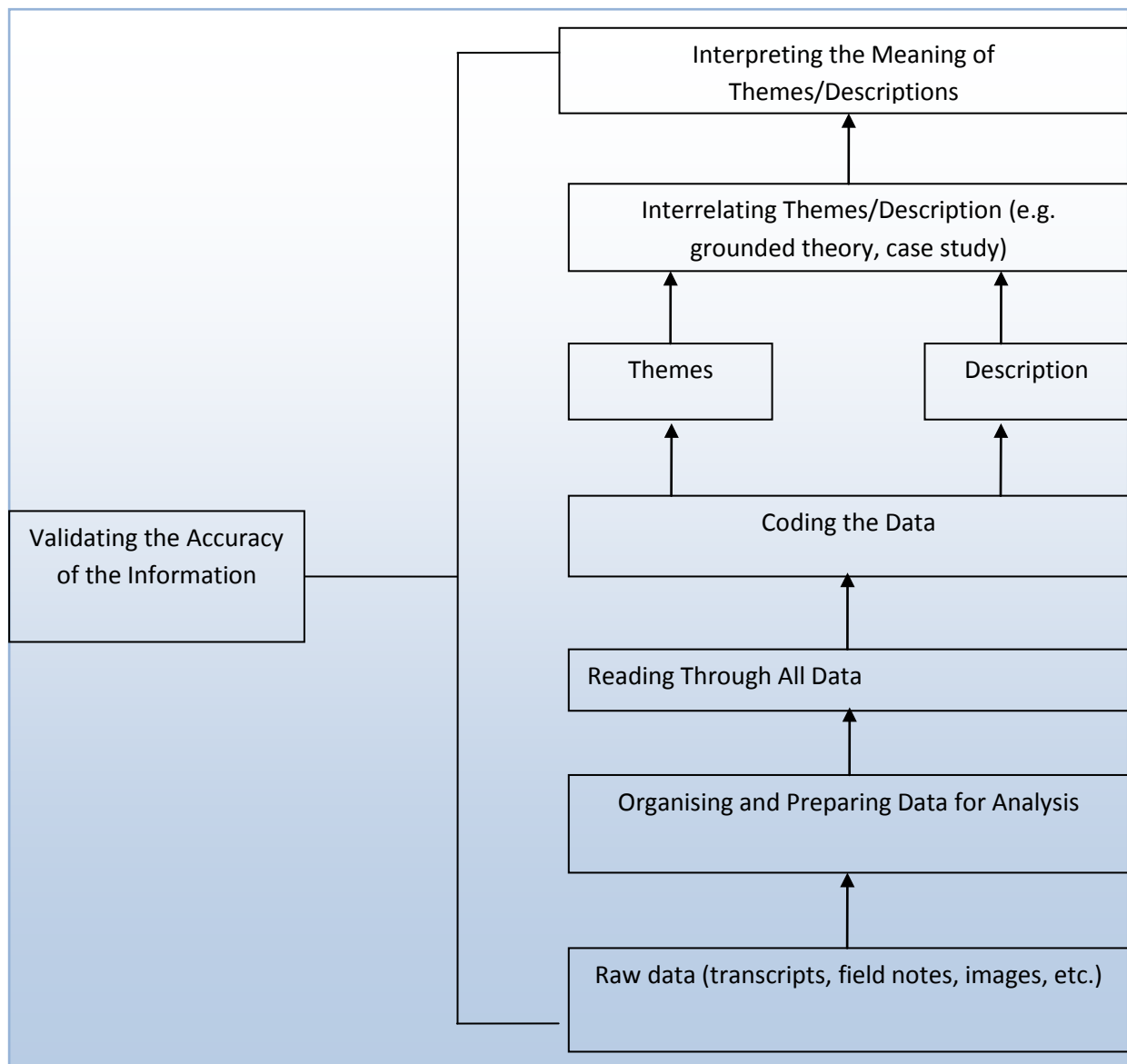
This study used Imogene King's Interacting Systems Framework and Theory of Goal Attainment, and in particular, the concepts of perception, communication, interaction,

transaction and role. The theory will guide the study in investigating whether service users' needs are met, their congruency with the C&HBC plans and strategy, and whether the interventions implemented translate to goal attainment in C&HBC. According to King (1981), good interaction and communication between service providers and users often attains the goal of efficient and effective transaction.

The study was conducted in the home settings of chronically ill clients on home based care, facilitated by health service providers, families and the community. The chosen study setting instigated the adoption of King's social systems concept, in order to explore other social determinants of health that relate to the effects of the environment in the provision of goal-oriented home based care services and delivery as well.

4.2 DATA MANAGEMENT AND ANALYSIS

Creswell (2009:183) describes qualitative data analysis as "a process that involves making sense out of text and image data and further involves preparing the data for analysis; conducting different analyses; moving deeper into understanding the data; representing the data and making interpretation of the larger meaning of data". The same author further describes the analysis as involving multiple layers of analysis, as shown in the figure below:



The approach to data analysis presented above should not be assumed to be linear, as is shown in the diagram. The different levels are interrelated in practice and can occur simultaneously or interchangeably. This was evident during data analysis for this research.

The focus group discussions and interviews for this study were analysed using NVivo software package. NVivo allows for the simultaneous organisation and analysis of content from several different interviews. NVivo creates a platform for deep analysis of data using powerful search, query and visualisation tools. Subtle connections to help justify findings can be made and the researcher gains more insight and ideas during the data entry process (Babbie 2010:412).

The method and procedure used during quantitative data entry and analysis was the following: the Data Entry platform was developed in the Census and Survey Processing System (CSPPro) using the format and structure of the questionnaire. CSPPro is a software package for entering, editing, tabulating, and disseminating data from censuses and surveys. CSPPro has a significant advantage over other data entry packages, in that it uses three associated programmes in one: a dictionary, a questionnaire (form) and logic. The dictionary is responsible for defining the data format in the entry programme, the form or questionnaire is then developed to be very similar to the hard copy questionnaire so as to minimise entry errors and improve on efficiency, while the logic contains the conditions associated with the actual entry, such as skips patterns and data validations.

For qualitative data from the two methods used in this study, data editing and analysis of content was done to prepare data for coding. The questionnaire was designed with response options that were coded prior to data collection. According to Babbie (2011:333, 338), “content analysis is the study of recorded human communication” and coding is “the transformation of raw material into a standardised form suitable for computer analysis”. Kumar (2011:257) and Corbin and Strauss (2008:160) further explain that in coding, quantitative information goes through transformation to numerical values, which are known as codes. Such information can be easily analysed and interpreted. Qualitative data goes through a process of content analysis, whereby themes or concepts are derived and codes can be assigned to the themes. The frequency of the codes can then be counted and participants’ responses incorporated into the report as quotes to support or negate findings.

The following section presents the findings of the study based on the combined analysis and interpretation of both quantitative and qualitative data. Neale (2009:278) advises against a tendency to emphasise one set of findings over another in mixed research methods. Therefore, the integration of findings from both methods will be utilised optimally. Content analyses, descriptive statistics and frequencies distributions were used to summarise and present data.

4.3 RESEARCH RESULTS



The results of the investigation into C&HBC programmes in Zimbabwe and the analysis of the congruency of service users' needs, along with the programme's goals, are presented and discussed under the sections detailed in the list below. The different sections are presented in themes and sub-themes derived from the research questions, objectives, content analysis and data coding exercises. The sub-themes include the following:

- Health experiences and needs of chronically ill service users
- Meeting service users' needs
- Satisfaction with services provided
- Key informants' perspective of service users' needs
- Health outcomes derived from care and support
- Capacity of C&HBC programme to meet needs and goals of chronically ill service users
- Participation and decision-making for the attainment of service users' needs and goals
- Comparison of rural and urban needs and services
- Challenges of C&HBC

4.3.1 Demographic characteristics

The demographic data collected and analysed from the structured questionnaires is presented in this section. This will include, age and gender specific information, educational background, marital, income and socio-economic characteristics of survey participants.

This information provides an understanding of the context in which participants experience their illnesses. Additionally, the demographic information exposes factors that affect access to health services, health-related needs, and other health behaviours. In line with Imogene King's Interacting Systems Framework and Theory of Goal Attainment, such knowledge and an analysis thereof will define levels of perception, interaction and communication with health providers.

Table 4.1 Distribution of survey respondents (N=206)

Residence	Care givers (n=61)		Service users (n=145)	
	Frequency	Percent (%)	Frequency	Percent (%)
Urban	46	75.4	96	66.2
Rural	15	24.6	49	33.8
Total	61	100.0	145	100.0

A total of 61 primary care givers and 145 C&HBC programme service users participated in the study. In total, 206 participants were enrolled in the survey. Three research assistants conducted the structured interviews in a manner that ensured privacy and confidentiality.

The study was conducted within settings that were familiar to participants, in order to ensure that minimal disturbance of their social and work responsibilities were incurred. At each study site, at least one focus group discussion was conducted with volunteer community care givers, primary care givers and ambulant service users, who have experienced chronic illness and home based care activities. A total of 12 focus group discussions were held with 110 participants. Thirty four key informant interviews were conducted, mainly at workplaces and homes of the interviewees.

Table 4.2 Demographic characteristics of survey respondents (N=206)

Demographic characteristics		Care givers (n=61)		Service users (n=145)	
		Frequency	Percent (%)	Frequency	Percent (%)
Gender	Male	12	19.7	38	26.2
	Female	49	80.3	107	73.8
Age	18-25 years	11	18.0	5	3.4
	26-33 years	5	8.2	17	11.7
	34-41 years	11	18.0	34	23.4
	42-49 years	11	18.0	48	33.1
	50-57 years	10	16.4	16	11.0
	57+ years	13	21.3	25	17.2
Level of education	Non-formal	10	16.4	15	10.3
	Primary	50	82.0	123	84.8
	Secondary	-	-	1	0.7
	Tertiary	1	1.6	6	4.1
Marital status	Single/never married	8	13.1	7	4.8
	Married	40	65.6	67	46.2
	Divorced/separated	1	1.6	9	6.2
	Widowed	12	19.7	61	42.1
	Cohabiting	-	-	1	0.7
Occupational status	Formal Employment	0	0.0	12	8.3
	Casual/informal Employment	17	27.9	23	15.9
	Farming	11	18.0	19	13.1
	Petty trading	10	16.4	43	29.7
	Unemployed	20	32.8	48	33.1

4.3.1.1 Age and gender

The majority of respondents (73.8% service users) and (80.3% care givers) are female. This skewed gender distribution is common in research in Zimbabwe, as a result of the absence of men in homes, due to the fact that they are out seeking employment or at work. Generally, men are less interested in health matters and are seldom present at health-focused gatherings (data from focus group discussion and key informants).

The majority (21.3%) of care givers are mature and older females, whereas the service users are generally in the working group between the ages of 34-49 years old. The age group between 26-33 years is less represented in the category of care givers and service users. This could be a result of their absence.

4.3.1.2 Education background

The educational level of an individual and that of a community plays a vital role in their health-seeking behaviours, their health goals, the health outcomes of the community, as well as how they respond to the health information disseminated. The majority of service users in the study (84.8%) and their care givers (82%) have attained minimal education at primary school level (seven years of basic literacy and numeracy). According to the Zimbabwe Demographic Health Survey (ZDHS), “the educational level of household members is among the most important characteristics of the household, because it is associated with many factors that have a significant impact on health-seeking behaviour, reproductive behaviour, use of contraception, and the health of children” (Zimbabwe National Statistics Agency (ZIMSTAT) & ICF International 2012:22).

The ZDHS highlights that the general education level is high in the country, with 78% of men and 70% of women having attended secondary school or higher; and that literacy levels stand at 94% for women and 96% for men (ZIMSTAT & ICF International 2012:51). This study found more respondents to have attained primary school level than higher levels of education, a result which is lower than what is stated in the ZDHS. The difference may be due to the environment in which the sample was taken. A common characteristic of the environment in which C&HBC is often implemented, is that it takes place amongst people of low socio-economic status.

4.3.1.3 Socio-economic status

Health inequities and access to health services are related to the economic status of households. Requirements such as medication, visitations to health facilities for diagnostic tests; treatment and nutritious foods (during periods of illness) all require a regular source of income. The graph in the next section shows the occupational status of study participants, which determines their level of income and ability to meet health needs.

4.3.1.4 Occupational status

An analysis of the occupational status of service users is important in this study, for an in-depth understanding of service users and care giver incomes, which may have a bearing on their access to health services, as well as upon meeting needs that affect their wellbeing and quality of life.

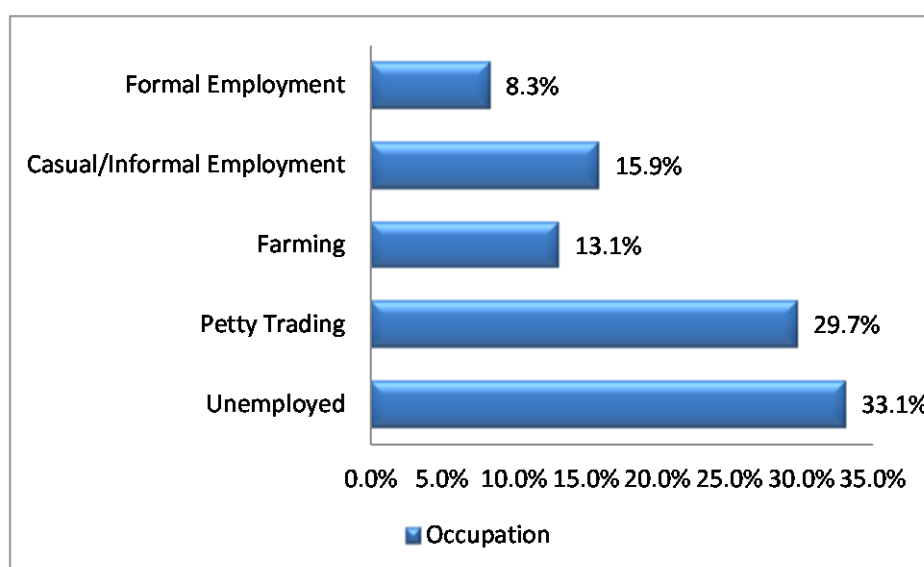


Figure 4.2 Occupational status of study service users (n=145)

Patients with chronic illnesses find themselves unemployed. Their inability to maintain a job may be due to their inability to maintain average performance level at work due to their illness, or to unpredictable bouts of acute illness. “Vending” or petty trading (the buying and selling of small items) is a highly rated activity among respondents (29.7%), many of whom are otherwise unemployed (33.1%). Income from such trading is generally low, but vending is less labour intensive and suitable for the unwell. Thirteen percent (13.1%) of respondents are involved in small scale farming as an occupation. Agriculture and farming are the main means of household income in Zimbabwe. However, since most farming activities are labour intensive, service users that are chronically ill face challenges when they undertake tasks in this sector (data from focus group discussion and key informants). The graph below shows the occupational status of family care givers.

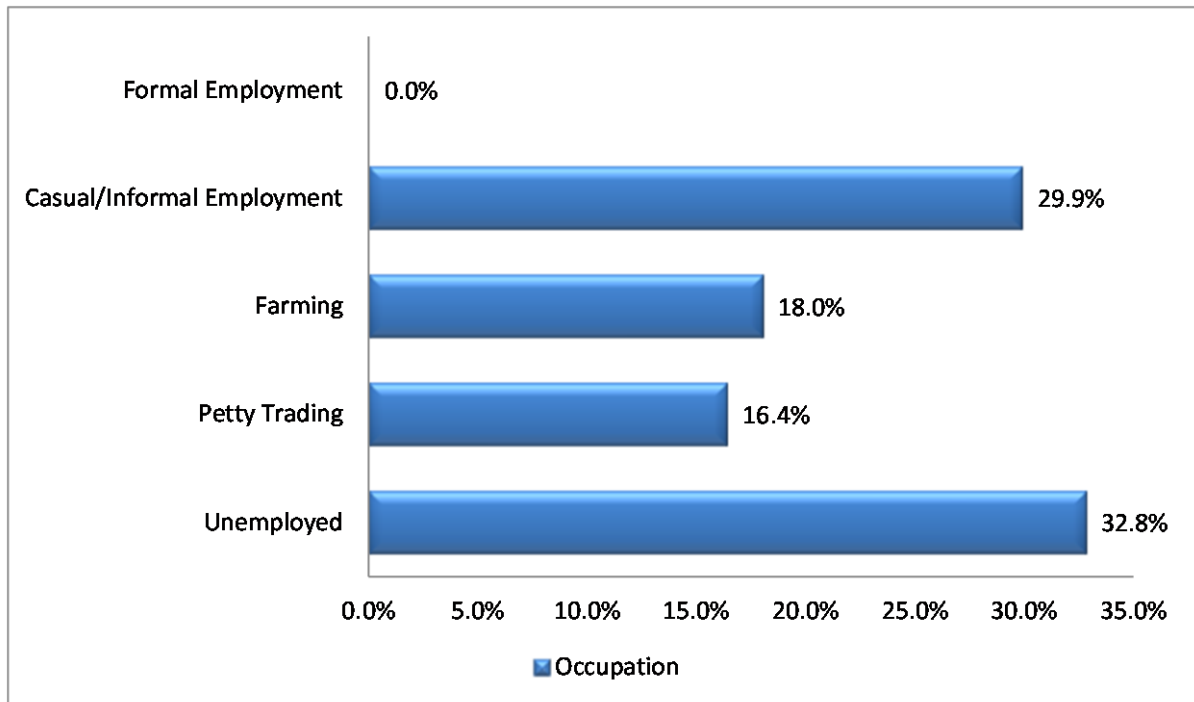


Figure 4.3 Occupational status of care givers (n=61)

Similar to the service users, 32.8% of care givers are unemployed. This could be attributed to their involvement in the caring process, or could be due to the low educational status (shown above), which prevents them from seeking formal employment. None (0%) of care givers are formally employed. Their stated means of earning income is through casual or informal labour (29.9%), which comprises part time employment, often in farms and as domestic workers (qualitative data from focus group discussion and key informants).

4.3.1.5 Income levels

An individual's income has a large impact on their health and access to basic needs and quality of life. Focus group discussion and key informants revealed that income earned by both service users and care givers is ploughed back into health needs and basic social needs of households, such as food and school fees for children. However, this amount is often insufficient even for basic needs. Data on service users' income was obtained from service users and is shown on the figure below.

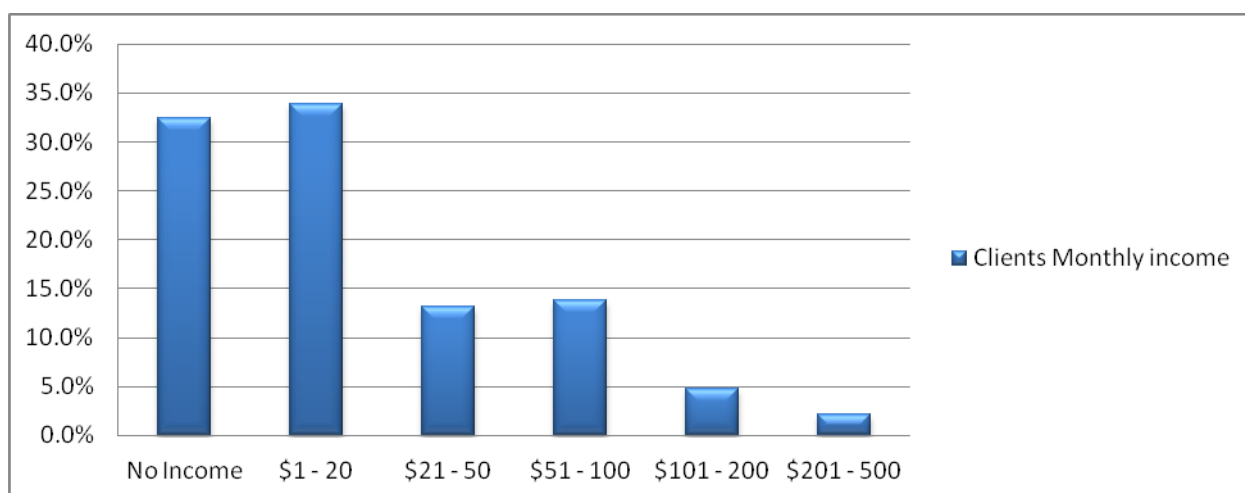


Figure 4.4 Service users' monthly income (n=145)

The graph shows 30% of service users with no income, and 35% earning an income of twenty USD or less per month. This amount is far less than the Consumer Council of Zimbabwe estimates, that set the average monthly household expenditure at US\$510 for a family of six (poverty datum line). Many people, including professionals, do not earn that wage per month (Consumer Council of Zimbabwe 2012).

The study also revealed that unemployed service users and care givers subsist on donations received from well wishers and from remittances provided by family members.

4.3.2 Health experiences and needs of service users

In order to understand the needs of service users within the context of their health problems, chronic diseases that are common in the communities under study have been explored here. This was done through focus group discussions, key informant interviews and through a survey questionnaire. In general, service users' were found to present with more than one ailment and several symptoms; some of which could be classified as complications of their conditions, or as a predisposition of conditions by which they were afflicted.

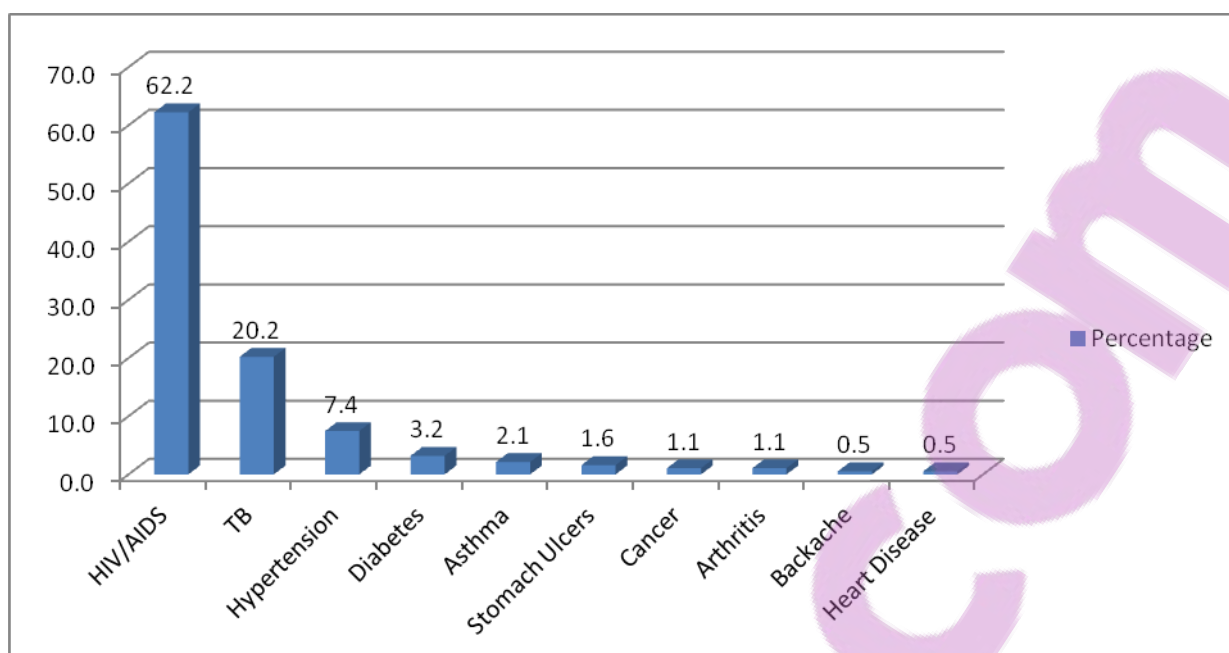


Figure 4.5 Distribution of chronic conditions among survey respondents (N=206)

The majority of service users enrolled in the study indicated having HIV or AIDS (62.2%), or are suffering from tuberculosis, which is a common HIV and AIDS related opportunistic infection (20.2%). The high prevalence of HIV and AIDS among those included in the study is observed to have had an impact on the findings, which are more inclined towards circumstances related to HIV and AIDS service delivery and care than those of other chronic conditions. However, hypertension and diabetes were reported as highly prevalent during focus group discussions and noted by key informants. FGDs also reported other medical conditions such as mental illnesses, asthma, neuropathy and cancers associated with HIV and AIDS such as karposi sarcoma and cervical cancer as common within the community.

4.3.2.1 Service users' overall needs

The survey found service users confronted by constraints that included physical challenges (56.6%), lack of financial resources (34.5%) and social problems (7.6%) as a result of experiencing long-term illnesses. The physical problems were related to symptoms of chronic illness and prevented service users from “achieving their life goals”. The social problems were related mainly to stigma, discrimination and inadequate socio-economic support from family and/or community. Financial constraints

were reported to emanate from unemployment and lack of income, which constrained their ability to pay medical bills, purchase food and achieve other important areas of their lives such as paying school fees for their children.

Service users specified what their needs have been as a result of chronic illness and being on home based care. The table below summarises the service users' needs and what they viewed would assist them meet their health goals if addressed. Multiple responses were given in table 4.3.

Table 4.3 Reported needs and expectations of Community and Home Based Care service users (n=145)

Service users' needs and expectations	Frequency	Percent (%)
To improve symptoms of pain, nausea, insomnia, etc.	61	42.1
To receive assistance with eating, dressing, and going to the bathroom	8	5.5
To receive information about their condition	26	17.9
To have better dialogue with care provider/s	5	3.4
To want respect for their privacy	2	1.3
To speak with a spiritual advisor	1	0.7
To feel more useful within their family	11	7.5
To eat well	78	53.8
To receive financial assistance	78	53.8
To access certain types of medication	6	4.1
To get counselling	3	2.1
To afford school fees, accommodation, exercise, wheel chair, start own business/project, gain weight, receive clothing	9	6.2

Fifty four percent (54%) of service users indicated their needs as food security. On further discussion with service users and family care givers, food was rated as the most needed item since antiretroviral medication and other regular medications should be taken with food. Service users also cited the need for financial assistance (54%) to pay for medication, which is not always free or readily available at public health institutions; hence the frequently stated desire (throughout the study) for economic security. Pain relief also rated as critical need (42.1%). These needs were also ranked highly during focus group discussions.

From the primary care givers perspective, 90% of service users discuss their needs with them and most care givers (62.3%) indicated that the requirements of service users are generally met. An NGO implementing C&HBC in one of the study sites was highly commended due to its ability to meet service users' physical needs. Families of the ill person usually meet the financial and other needs of the affected individual. Care givers also rated food and medication as the priority needs of service users.

In focus group discussions, needs similar to the ones discussed above were identified by service users and their care givers. The need for food was also cited as a priority. A key informant had this to say about the need for food in C&HBC: "People who are ill only think of food and their treatment". In addition, transport and transport fares to access clinics and hospitals for medical reviews was mentioned as challenges.

4.3.2.2 Meeting service users' health needs

Service users' indicated that their health needs were generally met, with 30% of respondents reporting their needs being met all the time; 30% having their needs met sometimes and 40% expressing failure in their needs being met by both family and the health delivery system. Families were generally found to have the responsibility of providing the needs of their sick relatives.

Service users' needs were also explored from the care givers perspective. Findings revealed that food security emerged as the priority need (49%). Medication was rated the second need (13.1%) and other financial needs (9.6%) were reported. Care givers also believed that (62.3%) of service users' needs were met largely through the extended family. However, Welfare Organisations were found to have made a significant contribution (19.7%) to the needs of service users and the overall implementation of C&HBC within the communities.

Key informants' perceptions (in particular the health professionals) was that needs are not often met according to their expectation. They cited frequent shortages of medicines, lack of transport to visit service users in need of their (health professionals) assistance, and lack of medical supplies (such as disinfectants, analgesics, wound dressing and gloves) for C&HBC requirements as barriers to meeting service users' needs. The quotations below sum up the challenges and the extent to which failure to

meet service users' needs and attain health goals are perceived by health professionals.

"We can do so much to reach the goals and meet the needs of service users as health personnel, but due to the poor social standing of service users, there are many things we are not in control of".

"We are meeting needs to a certain extent but not completely because many resources are not available".

"Government [led] home based care is not holistic because it's about health care only and neglects orphans and food provisions".

4.3.2.3 *Community and family coping strategies*

Information gathered from focus group discussions revealed that the burden of disease and care has forced communities to find various coping mechanisms for survival. Some coping strategies have been developed by the programme, such as the formation and sponsorship of "support groups" for PLH and those with AIDS and other chronic illnesses. These groups comprise people suffering from chronic illnesses and provide opportunities for individuals to share information, ideas and resources in a free atmosphere. However, many families were reported to be "doing the best they can through their own means with what they have" to survive.

Data showed that community health workers carry the burden of donating food provisions to destitute families from their limited resources out of compassion. Some NGOs provide limited food assistance for short periods of times through the World Food Programme.

Data also confirmed that families resort to herbs grown in herbal gardens, for the treatment of minor ailments and opportunistic infections when there is no money to buy prescribed medication.

4.3.3 Perceived service users' needs compared with available services

4.3.3.1 Community and Home Based Care programmes' response to service users' needs

From the literature review, it was evident that the C&HBC programme provides holistic services. The findings are that, though diverse, the services are not supporting service users to the extent expected. Service users also presented their needs and expressed the way in which they are benefiting from the service that aims to meet those needs. The table below shows service users' perceived needs and the differences regarding what remains as perceived needs and what is actually provided to service users. Participants gave multiple responses.

Table 4.4 A comparison of service users' needs and Community and Home Based Care support provided (n=145)

Service users' needs and expectations	No. reporting need	% of service users with the need	Support provided through the programme	No. reporting support	% supported
Food	78	53.8	Food assistance	36	24.8
Financial assistance	78	53.8	Finances	5	3.4
Improve symptoms of pain, nausea, insomnia, etc.	61	42.1	Medication	82	56.6
Receive Information about their condition	26	17.9	Health education	74	51.0
To feel more useful within their family	11	7.5	Support provided by family members	0	0.0
School fees, accommodation, exercise, wheel chair, want to start own business/project, gain weight, receive clothing	9	6.2	Referral to social services and other partners	0	0.0
Assistance with eating, dressing, and going to the bathroom	8	5.5	Provided by primary care givers	0	0.0
Access to other types of medication	6	4.1	Medication	82	56.6
Better dialogue with care provider/s	5	3.4	-	0	0.0
Counselling	3	2.1	Counselling	95	65.5
Respect for privacy	2	1.4	0	0	0.0
To speak with a spiritual advisor	1	0.6	0	0	0.0

More than 53% of service users have needs related to finances and food security. However, only 25% received food assistance and 3.4% financial assistance. Medication, health education and counselling needs are provided to a fairly large number of service users; hence they are not reported as pressing needs. Although the National C&HBC Guidelines (Zimbabwe MoHCW & NAC 2009:6) include spiritual counselling, adequate information and communication and respect for privacy as part of the provision of holistic care, these areas are not perceived as priority needs for most service users interviewed.

According to the National C&HBC Guidelines (Zimbabwe MoHCW & NAC 2009:21), basic nursing care tasks are the responsibility of primary care givers who are trained by community health workers in their execution, hence the findings above do not reflect that scope of activity.

From all survey results and both focus group discussions and key informant interviews, expectations from the health care system were centred on similar issues, ranging from the need for treatment, to financial needs. Specifically the expectations alluded to are food security, nutrition, medication and transport support; the creation of job opportunities by funding Income Generating Projects (IGPs) for self sustenance; the provision of counselling and spiritual support and access to diagnostic services such as x-rays, scanning and blood tests.

4.3.3.2 *Care providers' aptitude*

Community care givers are concerned about lack of regular additional training and acquisition of skills in simple diagnostic procedures such as checking of blood pressure, taking temperatures and administration of emergency medication, such as inhalers for asthma control and analgesics for pain management. One of the major needs identified by this study is that of symptom and pain management (an essential component of palliative care). Knowledge and practice of this aspect of care, which should be integrated into C&HBC according to the National C&HBC Guidelines (Zimbabwe MoHCW & NAC 2009:20), was confirmed as lacking during focus group discussions. It is the researcher's view that if secondary care givers and health professionals are equipped with such skills and implements them, some of the immediate needs of service users will be timeously met and in a cost effective manner.

Some health professionals from health facilities, however, indicated that their general training in nursing as well as on-the-job C&HBC orientation is sufficient for handling home based care tasks. Others were of the opinion that specific training on C&HBC should be provided to nurses.

4.3.3.3 *Satisfaction with services provided*

A Likert Scale (David & Sutton 2007:165; Bowling 2009:316) was used to gauge the service users' satisfaction with the care received in order to meet their health needs. The Likert scale ranges were: Strongly Agree, Agree, Uncertain, Disagree and Strongly Disagree. The score for each of the subscales were derived by averaging all the scores within that scale. All the response categories reflected positive findings (i.e. satisfaction with care) on the indicators of level of satisfaction with care and support in home based care. The majority of participants agreed or strongly agreed with statements reflecting quality of care provided, and disagreed or strongly disagreed with statements reflecting poor provision of care and support. The indicators used for assessment are listed in the box below.

Indicators of levels of satisfaction with care and support in home based care

Indicators

- Care providers are good at explaining about illness, care and treatment.
- The medical care received is just about perfect
- Easy access to health care providers
- Health care providers are very friendly and courteous
- Have some doubts about the ability of care givers.
- Care providers visit many times a month
- Dissatisfied with something about the care received
- Care providers sometimes ignore what the service user tells them
- Care providers are very competent and well trained
- Care providers should pay more attention to client's independence.
- Client always allowed to say everything that they think is important
- Visiting care providers should give more respect to clients

- Those who provide medical care sometimes hurry too much when they treat/care for client.
- Care providers involve service users in making decisions about own health care and needs.

From the survey findings discussed above, quality of care was regarded as generally adequate and of an acceptable/satisfactory standard. Home visits were found to be executed mainly by community health workers (85.5%) who visit infrequently. Ten percent (10.4%) of visits were by nurses and 4.1% by social workers. Nurse-key-informants repeatedly cited lack of transport resources as the cause of failure to visit service users. Service users who reported no visits from care providers (9.4%) were those whose condition had improved.

4.3.3.4 Key informants' perspective of service users' needs

Data from health professionals interviewed and other key informants revealed their own perception of service users' needs, based on interactions and experience in community health services as indicated below.

Pain management and availability of medicines for treatment of various ailments

Many service users are reported to be in need of strong analgesics which are provided as part of palliative care. This area of care has been neglected, although critical in the nursing of chronic conditions, and many patients suffer with pain silently and are thus deprived of their right to relief and eventual death with dignity.

A safe and welcoming environment to be discharged to

This aspect of care, found to be a need in C&HBC, is not adequately understood and addressed by the health system. It is likely to be the result of poverty, stigma and discrimination of chronic illnesses especially HIV and AIDS within families. Although health education is provided on a range of topics affecting psychological health and health care, the extent and coverage was not explored in this study. Other social obstacles are likely to contribute to non-conducive environments for the chronically ill receiving home based care.

Financial assistance to cover medical expenses, transport and food

The majority of service users are breadwinners, who have lost income as a result of illness, and their care givers are unemployed. The burden of financing medical expenses has resulted in greater poverty and a failure to purchase basic needs such as food.

Food as a nutritional requirement and for those on powerful medication that affect the gastric system such as antiretroviral drugs

Food should consist of a balanced and palatable diet. Some service users fail to access such a diet due to an extreme lack of means and resources.

Adequate medical care supplies for wound dressings and universal precautions

Service users rely on these supplies for palliative and basic care at home, without which home based care becomes meaningless. Such provisions are regrettably in short supply.

4.3.3.5 Linking care givers' needs to care provided

The study also explored the needs of care givers, which are likely to be intricately linked to those of their clients (Kang'ethe 2009:28). This was done for deeper understanding of service users' needs and expectations of care and support.

Primary care givers reported requiring training in basic nursing care as well as in communication skills, for effective interaction with service users. A broader understanding of home based care was also reported as a major need.

Secondary care givers cited the following C&HBC-related supplies as their major need for effective care and support of service users; paracetamol for pain relief, disinfectants, protective clothing including gloves as well as medicines and bandages for wound dressings. They also cited the need for incentives/allowances for motivation and for their own sustenance. Akintola (2011:60) also suggests that home based care programmes run the risk of poor performance if there is a mismatch between the care

givers' motivation and organisational goals. Other scholars (Rödlach 2009:429), including Akintola (2011:56) claim that care givers volunteer for a range of reasons that are based on their individual and social needs, and also on having shared organisational vision and goals (Osawa, Kodama & Kundishora 2010:901).

In an analysis of the challenges influencing the state of care giving in the Kanye community home based care programme in Botswana, Kang'ethe (2009:29) states that the poor socio-economic circumstances of care givers may have negative effects on the care they provide as a result of eroded dignity and self esteem. Similarly, lack of medical supplies for basic nursing care is likely to reduce the confidence that service users have in them as competent and effective care providers, in addition to the basic failure to meet service users' needs.

Health professionals cited the need for efficient support of C&HBC. The major need repeated many times during field visits was that of resources, especially transport to carry out home visits for follow up care, and also to support community health workers in the community.

4.3.4 Capacity of Community and Home Based Care programmes to meet needs and goals of service users

According to key informants interviewed from the MoHCW, delivery of C&HBC services is guided by a national C&HBC strategy, which stipulates the roles and responsibilities of all service providers. The MoHCW (working through the National AIDS Coordinating Programme), oversees and coordinates the activities of all stakeholders and provides policy and technical support in training of care givers. This was also confirmed through literature review.

Community health workers and primary care givers are mandated with the role of assessing service users' needs; with the provision of physical care and counselling; with ensuring adherence to drug regimens; provision of information and education; assisting with household tasks; and with the provision of spiritual support. Of these activities, assessment of service users' needs was reported by the majority (73.8%) of primary care givers as key to their activities, followed by provision of limited health education (29.5%) to service users.

Focus group discussions with service users, primary care givers and key informants revealed further information on their perceptions regarding services provided and areas that require strengthening. A key informant's response on their view of the programme is quoted below:

The C&HBC strategy is addressing the needs of service users because there are still those very ill service users who require what is in the strategy e.g. bedridden clients. The strategy was based on service users' needs although naturally some aspects of it were thought out by those who drafted the strategy. (Key informant).

When asked about their experience in relation to the C&HBC goals and whether the programme is perceived to be meeting those goals, several key informants were of the opinion that goals are being met to a limited extent and in some of the areas. Since the government relies mainly on donor support for C&HBC implementation, the barriers to effective implementation are mainly linked to the limited financial and human resources.

The programme goal has shifted according to the needs of service users and the trends in C&HBC. Home based care [implementation] has shifted as a result of the scaling up of ART. Implementers don't seem to understand the implications and importance of C&HBC and are scaling down its support especially donors. ART will flop if HBC stops. (Key Informant).

4.3.5 Health outcomes derived from care and support

Health outcomes in C&HBC can be defined as the goals intended by the programme and anticipated by service users enrolled in the programme. The quality of life, service users' physical function, the absence of, or reduced symptoms are viewed as indicators of positive outcomes. These were also used in this study as measures to ascertain the process of meeting long-term care needs, and to assess the attainment of service users' goals.

4.3.5.1 Perceptions of quality of life based on services received

In this study, quality of life was found to be a personal experience for each participant and based on individual needs. For example, a female service user who had HIV and TB as well as being partially blind, wanted (as her goal) to recover and return to work as a vendor, but was constrained by the blindness. The participant believed that her quality of life could only be enhanced if the social welfare authorities issued her a letter for free treatment and the provision of free spectacles.

The following quotes were commonly used as descriptions of the quality of life expected by many respondents:

Getting better and working for myself and not being a beggar.

Having a good [healthy] diet, good health, shelter, access to medication, self care.

Having peace of mind, being able to walk and socialise with others without discrimination.

Having peace of mind – it is not important to have material things whilst you are not settled in your mind.

Being able to do things on my own such as walking, bathing then going to work.

Having what I want, a job, and be able to take care of my family and to send children to school.

Good living. Being able to do what you want and buy/get what you need.

Having a good job that pays me money to support the family and going for checkups.

The illustration that follows in a pie chart below shows a summary of respondents' views on what quality of life means to them:

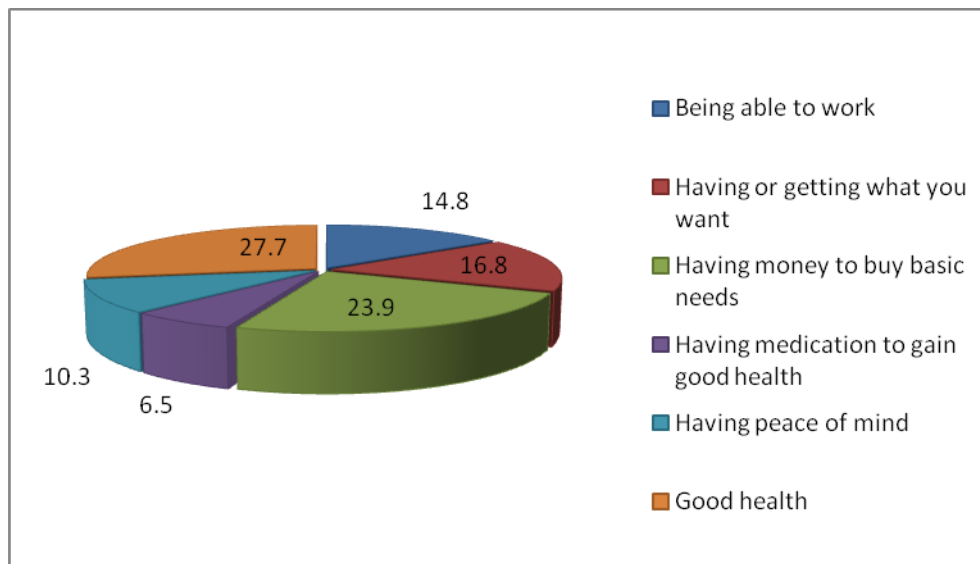


Figure 4.6 Service users' views on the meaning of quality of life (n=145)

Twenty seven percent (27.7%) of service users participating in the study defined quality of life as having good health and 23.9% as "having money to buy what one wants". Quality of life is perceived by few respondents (6.5%) as the capacity to access medication.

Perceptions of quality of life were found to be based on health status and the capacity for financial sustenance. It appears that service users and their families prioritise certain basic human needs more than medication and other health matters, which become second priority when discussing quality of life issues.

When asked to self-evaluate their health status at the time of interview, using a score of excellent (normal health), very good (near normal health), good (minor health problems), fair (many health problems), and poor health (no improvement in health status), participants rated their health status as shown in the bar chart below.

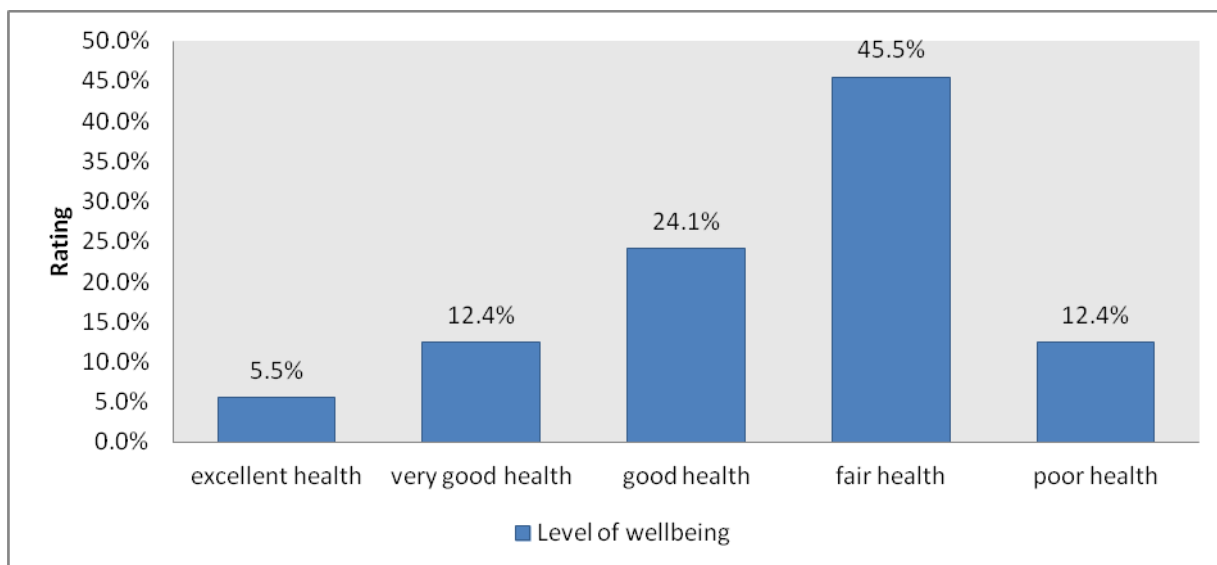


Figure 4.7 Service users' health status (n=145)

From the above analysis, the majority of respondents experience 'fairly good' to 'good' health, which reflects a generally satisfactory health status and indicates a better quality of life. The health status was attributed to C&HBC services, which meets some of their needs. When asked what specifically resulted in their improved health status and subsequent improved quality of life, the reasons in the pie chart were identified.

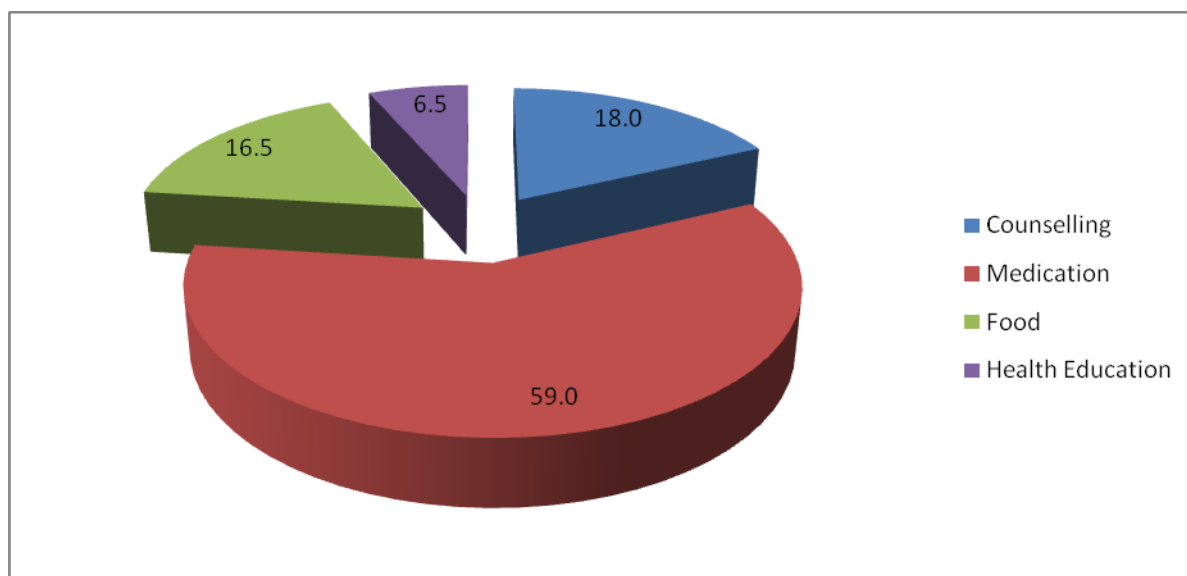


Figure 4.8 Service users' reasons for improved quality of life (n=145)

The pie chart above shows that access to medication (59%) is perceived as having played a critical role in improving the wellbeing of service users. Medicines are

generally provided for in-health facilities, although there are challenges when medicines run out of stock and when there is a lack of financial resources to purchase the required medicines by service users. Health education is not perceived as essential to improvement in health (6.5%). This raises concerns regarding the extent to which it is given to C&HBC service users, or how service users interpret the provision of health education as a part of the process of care and support.

The majority of participants (77.2%) attributed the improvement in their quality of life to the C&HBC programme services. Of these, 55.9% viewed their ability to walk and eat as indicators of improvement in their health status and consequent improvement in the quality of life. However, 22.8% of participants had not experienced a change in their quality of life, despite being enrolled in the C&HBC programme. Approximately 10% of participants had experienced some deterioration in their health since enrolment into the C&HBC. This is not uncommon, for reasons such as poor prognosis, lack of adherence to treatment regimens, and natural progression of disease. The participants, however, perceived the deterioration to be a result of lack of food and medication.

4.3.6 Participation and decision-making for the attainment of service users' needs and goals

Imogene Kings Interacting Systems Framework and Theory of Goal Attainment (King 1980) focuses on the interaction between service user and provider as a means of mutual understanding, leading to the attainment of goals. Autonomous involvement without fear by the service user is therefore necessary for the effectiveness of interaction.

From the assessment of choice of care provider assigned to service users, findings showed that 116 (80%) of service users were not involved in the choice of their community health worker on their enrolment into C&HBC. Community care givers are assigned to a service user by nurses (80.3%) based on where a service user resides and family care givers were obliged to care for their own sick relatives. Primary care givers assigned to care for sick family members were fewer (6.6%) than those that volunteered (13.1%), or were driven by compassion to care for their own sick relatives. Moreover, of the primary care givers, 51.4% had not received any form of training in nursing or care of the sick. Service users' choice of a care giver is likely to determine

mutual trust and effective communication of needs and goals between service user and the care provider.

From the perspective of the majority of community care givers, health decisions regarding service users' care are often made with the family in the absence of the service user. This was indicated by 45.9% of respondents. Only 41% of decisions are made with the service users' involvement. In focus group discussions, both service users and key informants expressed dissatisfaction with the adequacy of participation in decision-making by service users and families in C&HBC. Focus group discussions with service users raised the following issues regarding participation:

We are left out in decision-making because we are considered too sick to make decisions.

There is stigma and discrimination of chronically ill people in families.

Involvement in family decisions depends on your relationship with the family.

We don't really have a system for participation. We are afraid to question issues and don't know what to do.

However, key informants pointed out that there are mechanisms in place for community involvement within the health sector. These include community health committees and suggestion boxes. In C&HBC, community health workers have the mandate to report service users' needs to health professionals at health facilities for advice and technical support. However, this mechanism is not always efficient. This is supported by findings from Uganda which showed that those tasked to represent the communities' health needs were not doing so. In addition, information and requests made through "suggestions boxes" at health facilities were not responded to as health providers considered them "personal" rather than pertaining to community needs (Rutebemberwa, Ekirapa-Kiracho, Okui, Walker, Mutebi & Pariyo 2009).

In this study, professional nurses at the municipality clinics cited the under-usage of "suggestion boxes" located in strategic positions within the premises, as evidence of a reluctance or unfounded fear by service users in airing their views on treatment and care. This system of anonymous interaction with the health delivery system is meant to avoid personalisation of issues which occur during face to face interactions, which may

raise anxieties about confidentiality. Chronically ill persons tend to have complex needs and matters that need to be handled confidentially.

4.3.7 Comparison of urban and rural findings

The section that follows analyses some of the issues relevant to this study's research questions and objectives and is based on a comparison between the rural and urban settings under study. Knowledge of differences or similarities is useful for planning and designing relevant and appropriate programmes for the different settings.

The study endeavoured to explore the differences in the needs, expectations and level of support of C&HBC service users in urban and rural areas. The approach to rural and urban C&HBC interventions is generally similar in Zimbabwe. However, from the researcher's experience and available literature review, the experiences and constraints in access to services as well as coping mechanisms of service users and their families, differ between rural and urban settings.

4.3.7.1 Demographic characteristics

The break down from the total number of participants surveyed in the study is that 96 service users were from urban areas and 49 from rural areas. There were 46 care givers in urban areas and 15 in rural areas. The table below shows the percentage distribution of participants by geographic locale.

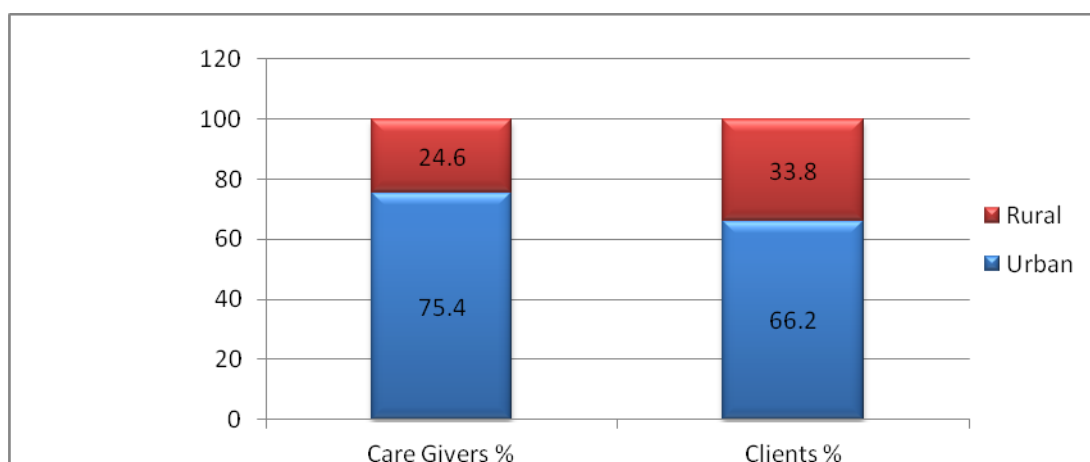


Figure 4.9 Geographic distribution of survey participants (N=206)

More service users and care givers were interviewed in urban than rural areas. With the health of service users improving as a result of increased access to ART and more previously bedridden service users accessing it, many individuals as well as their care givers are relocating to urban areas in search of jobs.

4.3.7.2 Community and Home Based Care services provided

From the response of focus group discussions and key informants, it was established that rural care givers and service users appreciate the service more than their urban counterparts. Secondary care givers in rural areas are driven by compassion and duty to care for the sick, whereas there were frequent complaints about lack of incentives by urban care givers, causing complacency in regular visits and care to service users. The sparse distribution of homes and clinics in rural areas, however, hinders care givers from linking up with service users and health professional on regular basis. The rural sites visited for this study are situated approximately 20 kilometres from the nearest health centre, and there is no public transport. This situation is likely to reduce the extent to which physical, emotional and other core health needs of service users are handled timeously.

In focus group discussions with service users and their care givers, there were more appeals for a system of regular handouts ranging from food, clothing and rent in urban setups; whereas in rural areas, service users and care givers preferred to work for themselves to earn a living. Respondents appealed for assistance in form of loans for income-generating projects. There is therefore potential in rural areas for ensuring means of sustenance in order to meet medical care needs in chronic illness.

4.3.7.3 The needs and expectations of service users by geographical setting

The quantitative survey also showed some significant variations and similarities in the needs of urban and rural service users. The graph below shows a comparison of service users' needs in rural and urban areas. Participants gave multiple responses.

Table 4.5 A comparison of urban and rural service user needs

Service users' needs	Urban (n=96)		Rural (n=49)	
	No	Percent (%)	No	Percent (%)
Improve symptoms of pain, nausea, insomnia, etc.	43	44.8	26	53.0
Assistance with eating, dressing, and going to the bathroom	8	8.3	0	0.0
Receive Information about their condition	21	21.9	5	10.2
Better dialogue with care provider/s	5	5.2	0	0.0
Respect for privacy	2	2.0	0	0.0
To speak with a spiritual advisor	1	1.0	0	0.0
To feel more useful within their family	10	10.4	1	2.0
Food	51	53.0	27	55.1
Financial assistance	57	59.3	22	44.9
Counselling	3	3.1	0	0.0
School fees, accommodation, exercise, wheel chair, weight gain, clothing.	7	7.3	2	1.0

The table above shows similarities in service users regarding an increased need for relief of unwanted symptoms, including pain (44.8% urban vs 53% rural) food (53% urban vs 55.5% rural) and financial assistance (59.3% urban vs. 44.9% rural). However, urban communities' quest for financial security is greater than of those in rural areas. The need for financial resources is often greater in urban than rural areas. Rural service users are less concerned with comforts or interventions such as being assisted with eating, dressing up, and going to the bathroom; receiving information regarding their condition and feeling more useful within their families, than are their urban counterparts.

Furthermore, 24% of service users from all areas mentioned the lack of support from their families. Of these, 72.2% were from urban areas and 27.7% from rural areas. The support rendered is either largely financial or given by means of food provision (both settings), and assistance with household chores and counselling in urban areas. The above pattern could be the result of the ability of rural communities to cope better and more collectively through difficult circumstances than urban dwellers. The social support network is still stronger in rural than urban areas despite documented disintegration of social support systems within rural settings in general (Caring from within: ... 2008:15). The following graph reiterates the service users' needs discussed above and the rural/urban differences. In response to the question "what are the main problems you are facing as a result of your illness?" Service users presented the following problems:

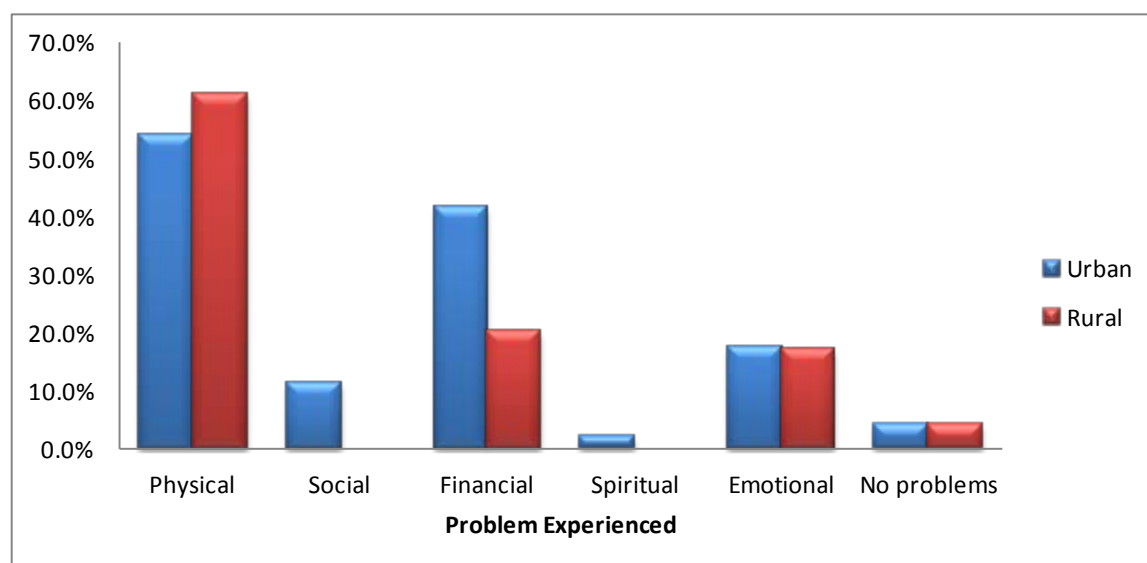


Figure 4.10 Description of problems faced by rural and urban service users (n=145)

Physical problems are common in both rural (61.2%) and urban (54.2%) settings. More service users in urban areas face economic problems (41.7%) than in rural areas (20.4%). Spiritual support is assumed to have less demand and is not viewed as a priority need in health and well being as seen from the low score above.

The perennial 'clamour' about financial inadequacies is further shown in the graph below, comparing rural and urban income levels.

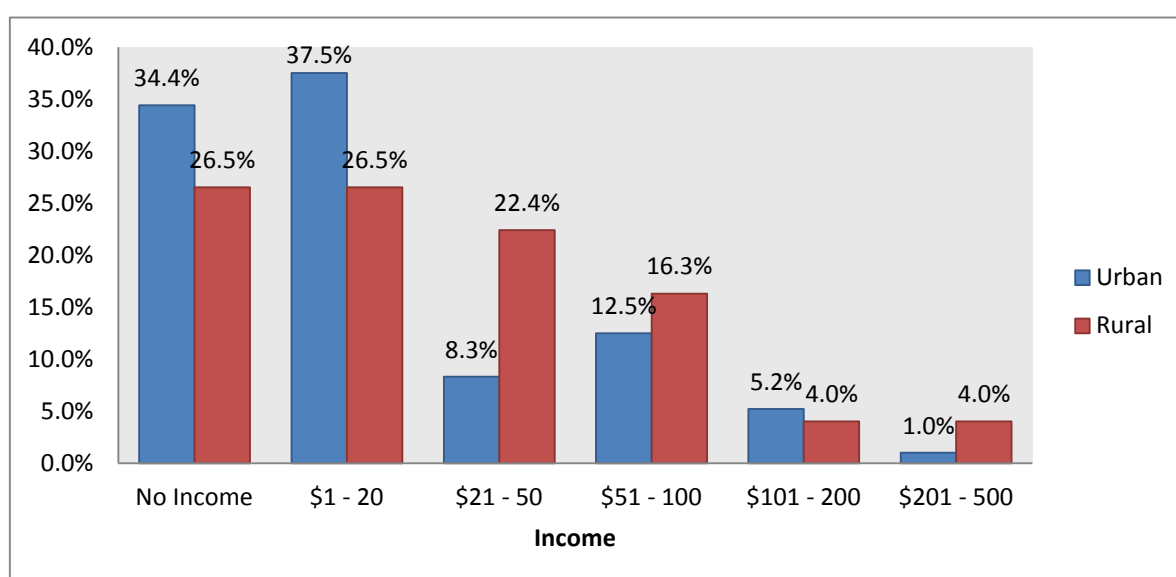


Figure 4.11 Distribution of service users' monthly income by rural and urban settings (n=145)

Few respondents have income levels of at least US\$50 and above per month in both urban (16.3%) and rural areas (12.5%). There is a higher income in rural areas than in urban areas. More service users in urban areas have an income of between US\$1.00 – \$20.00 per month (71.9%) when compared to rural areas (53%). These findings can be attributed to the small scale farming in rural areas and the resulting income from those activities, than is the case in urban areas. Furthermore, people move to urban areas seeking jobs that may not be available due to the depressed economic growth in the country. Many urban-based individuals often resort to working in menial jobs that provide little income.

During a further search for an explanation regarding the problems and needs of service users in the C&HBC, the study revealed that stigma and discrimination exist more in urban areas than in rural areas, where there is no longer a need to worry about it. Service users in urban areas face the need for protection against stigma and discrimination. Lack of financial means to pay for diagnostic tests was also a common need in urban areas where such services are provided.

Comprehensive health care requires travelling back and forth by health providers and patients for the purposes of interaction, care and support. In focus group discussions, transport to access health and social services was identified by all groups as a dire need, whether in rural or in urban areas.

In summary, the researcher can conclude from this section that the most outstanding needs for service users are food, financial assistance and relief from the negative symptoms of chronic health, including pain, irrespective of geographical area. C&HBC needs within rural and urban settings are sometimes situational and relate to the environmental dynamics such as long distance from health services and the need for transport. Although differences were found, their significance to the setting and attainment of service users' health goals is limited.

4.3.8 Perceived overall challenges of Community and Home Based Care in the study sites

Respondents were asked to indicate the general problems faced by families of the chronically ill that may affect health outcomes. Many of the challenges disclosed were

found to be similar to those uncovered during literature review. An analysis of these challenges places them as key determinants of success in meeting the needs and goals of service users enrolled for home based care. These challenges are presented and further evaluated against service users' needs below.

Table 4.6 Challenges of Community and Home Based Care and their effects on service users' needs and goals

Challenge raised by respondents	Effect on meeting service users' needs and goals
<ul style="list-style-type: none"> • Inability of service users to buy prescribed drugs that are not available or out of stock at health facilities, due to lack of financial resources. 	<ul style="list-style-type: none"> • The priority need for sick individuals is treatment with medication. • Nurses can only meet health needs when financial and other resources are available. • Patients fail to adhere to drug regimens leading to drug side effects and complications.
<ul style="list-style-type: none"> • Shortage of home based care supplies (kits). (These are passed on to service users by community health workers). 	<ul style="list-style-type: none"> • These are essential items for basic treatment and care required by bedridden and terminally ill patients.
<ul style="list-style-type: none"> • Diverse social situations, values, beliefs and practices in service users' homes. Abandonment of service users with chronic illnesses by relatives. 	<ul style="list-style-type: none"> • Stigma and discrimination experienced by service users prevents access to care and support. Service users who are renting houses are known to refuse to disclose their residential addresses and miss out on visits by health providers at home out of fear that the landlord will evict them from the premises once a stigmatised condition is exposed.
<ul style="list-style-type: none"> • Poor economic stability, poverty and lack of livelihood among service users and their families, especially if the service user is a breadwinner. 	<ul style="list-style-type: none"> • Families cannot afford diagnostic tests, transport fares to access health services, medicines, food and others items of comfort.
<ul style="list-style-type: none"> • Lack of food security especially in homes with the elderly and child-headed homes. When WFP food handouts run out or when patients are discharged from the food programme, they look for food assistance at clinics. 	<ul style="list-style-type: none"> • Food provides nutrition for the body and is required to build the immune system during illness. Some medicines cannot be taken on an empty stomach. Food is a basic need.
<ul style="list-style-type: none"> • Long distances between health facilities and the community. 	<ul style="list-style-type: none"> • Health professional provide proficient assessment of service users' needs and should be in the forefront of doing

Challenge raised by respondents	Effect on meeting service users' needs and goals
<ul style="list-style-type: none"> Lack of transport facilities for patients to visit clinics and for health professionals to visit homes. 	<ul style="list-style-type: none"> assessments. Service users' needs such as, strong analgesics for palliative care can only be provided by professional nurses. Easy access to health facilities is required for emergencies.
<ul style="list-style-type: none"> Many service users are cared for by children and youth. Lack of skills to care for certain conditions such as mental illness etc. Lack of knowledge by primary care givers of nursing care skills for specific conditions. 	<ul style="list-style-type: none"> Children and young people cannot provide for adult needs efficiently. Only skilled people in a particular field/area can provide relevant care.
<ul style="list-style-type: none"> Lack of reliable and appropriate referral organisations in some programme areas. 	<ul style="list-style-type: none"> Since health facilities cannot meet the social needs of service users they refer them to NGOs in the area. However, the needs are usually not met because the NGOs have their own mandates and thus cannot attend to the real and practical needs of the community and patients.

4.4 OVERVIEW OF RESEARCH FINDINGS

The study utilised multiple methods and sources of information. The triangulation of data maximised the chances and confidence of having obtained sufficient understanding of goal attainment in C&HBC, through addressing the service user and their interaction with the health system. Home based care programmes were recognised and escalated as a result of the need to reduce bed occupancy by patients suffering from HIV or AIDS. It is unsurprising that the majority of service users presented with HIV and AIDS.

Data was presented both qualitatively and quantitatively. Comparisons were made where necessary for deeper understanding of results in order to inform valid conclusions.

C&HBC is not meeting the needs of its service users completely. Chronic diseases are many and varied. Service users have diverse needs, and goals depending on the

specific condition and symptoms they experience. It is possible to address symptoms and basic nursing care needs through improvising and other simple remedial means. However, there are those needs that require expensive, carefully managed and targeted resources. The socio-economic environment plays a large role in determining patients' needs, experiences and outcomes of their illness. This determinant of health cannot be ignored, and needs to be addressed from a development perspective.

Generally, findings of this study corroborate those that demonstrate unmet social needs (Futeran & Draper 2012:9). However, the same studies showed that medical needs were met according to service users' expectations.

4.5 CONCLUSION

This chapter provided an investigatory and descriptive analysis of the C&HBC provision in Zimbabwe, based on the research questions, aims and objectives of the study. The findings were presented in themes derived from the research question, aims and objectives of the study. The study explored whether C&HBC implements interventions and provides services that meet users' goals. It further explored and described the health care needs and experiences of chronically ill service users enrolled in the C&HBC programme.

From the data analysis and review of the literature, there is a consistent finding that study subjects perceive access to medication for symptom management and pain control, food and financial stability, as priority needs of service users and their care givers and health providers. The services provided are generally in line with the physical needs of service users. However, they are deficient in addressing the socio-economic and psychosocial needs of service users.

Discussion of findings and application to policy and programming are discussed in the next chapter.

CHAPTER 5

STUDY DISCUSSION

5.1 INTRODUCTION

This chapter will further explore and synthesise the findings of the study, and present conclusions and recommendations for policy and programming in C&HBC initiatives in the Zimbabwean context. The chapter will also discuss the theoretical framework, limitations, and implications of findings for nursing practice, and provide recommendations for future practice and research.

The need for this study arose out of concern that the issue of the growing number of people living with chronic illnesses, and being cared for at home, is not receiving appropriate attention from health services, especially in relation to their needs and expectations in achieving expected goals. The demands of chronic illness are sometimes complex, especially in the era of HIV and AIDS, which has added a social dimension to health problems. As ART is scaled up countrywide, PLH and those with AIDS require interventions that are increasingly tailored to ensure that the benefits of ART are maximised. This study sought to examine to what extent the C&HBC services provide for the clients' needs as service users. Consequently, it was essential to also determine in this study whether communities are adequately skilled to be more active, and not just to become passive end-users of the services provided.

As mentioned earlier in the study, governments are accountable for their citizen's health and should therefore ensure the fulfilment of their health needs and goals. To what extent this stewardship is exercised through strategies and plans implemented in C&HBC is explored and discussed here.

The findings have revealed the extent of care required according to service users' needs; the quality of care, and indicators of positive outcomes from the service users' perspective. The findings also revealed the complexity between needs that result in

positive health outcomes and perceived needs that have no plausible basis (or those based on “wants”).

The research proposed to answer the following three questions:

- How does the current delivery of C&HBC meet service users’ needs and expectations?
- What is the extent of community participation and decision-making that guarantees attainment of service users’ needs and goals, as well as expected health outcomes (the secondary goal of social development)?
- What are the key areas of need that have been identified to develop a guideline for harmonising service users’ needs and expectations with the health delivery system for goal attainment?

5.2 RESEARCH DESIGN AND METHOD

The purpose of this cross sectional explorative and descriptive study was twofold; firstly to explore whether the C&HBC intervention provides services that effectively meet users’ goals in an evolving social environment, and secondly, to utilise the findings of the study to develop a protocol for harmonising service users’ needs and expectations with the health delivery system for goal attainment. A guideline for integration of C&HBC in the health delivery and social system, which is the last objective of the study, is presented in chapter 6. It focuses on three concepts namely: i) integration and harmonisation of services to meet the needs and goals of users; ii) interaction between service provider and service-user; and, iii) community capacity and engagement. The themes are in line with Imogene Kings’ Interacting Systems Framework and Theory of Goal Attainment, which have provided part of the conceptual reference underpinning this study.

To achieve the objectives of the study, a mixed-methods research design was used. Two instruments to gather quantitative data were developed. The first instrument was for service users who had been enrolled in a home based care programme, and the second instrument was for primary/family care givers of the service users identified. The semi-structured questionnaires were administered by trained research assistants. Quantitative data was gathered from community health workers and service users

through focus group discussions. Data was also collected from policy makers, professional health workers and “significant others” (key informants) through in-depth interview guides. Since there is limited literature on studies similar to this one, the researcher developed new guides and questionnaires with reference to relevant questions from other studies with a comparable focus. The tools were pilot-tested for validity.

The mixed-method design was chosen because of the nature of the study, which explored a complex phenomenon of diverse needs and expectations of chronically ill people being supported through the implementation of a single intervention strategy. Ethical considerations were taken to safeguard participants’ rights in accordance with standard ethical principles of human subjects’ research that are stated in chapter one of the study.

Two settings were chosen for the study, and these comprised a rural and an urban area. Participants were selected on the basis of their age; on having a chronic illness and being on home based care; and, not being impaired by poor health status.

5.3 SUMMARY AND INTERPRETATION OF RESEARCH FINDINGS

The following chapter will discuss the interpretation of findings from previous chapters. The discussion will follow the themes used when presenting the study findings in chapter 4.

This study showed a predominance of service users with HIV and AIDS and other related conditions. The inferences from the findings may therefore have a bias towards HIV and AIDS home based care programmes, although much consideration will be given to C&HBC for other non-communicable chronic illnesses.

5.3.1 Health experiences and needs of service users

While the government-designed C&HBC programme addresses a significant portion of service users’ needs, it is evident from the findings that economic well-being, the need for food, and balanced or suitable nutrition as well as appropriate interventions for pain and symptom management, are a challenge to service users and their families and to

health service providers. The study revealed that service users do not separate their social needs from their health needs. This proves the generally-assumed interconnectedness “in the real world” between health issues and the needs expressed by study respondents. (WHO 2008b:10; Bowling 2009:65). Service users’ needs tend to be subjective and are bound to change over time in relation to the influence of social, cultural and economic factors. It is evident that the socioeconomic situation in Zimbabwe has constrained patients and limited their care givers’ abilities in providing the required health care.

The emotional state of service users is normally positively affected by a conducive socio-economic environment, and this has played a big role in the overall well-being of service users and their families. This is the need for “peace of mind” referred to by service users throughout the research. Despite these challenges and the work still required to be done, the health needs of service users are currently addressed to a level where they derive “some comfort” with their health status. The researcher is of the opinion that if social needs are not met, then the overall health goals cannot be fully realised. However, the needs identified in this research appear universal, and appear to corroborate findings from studies from other countries showing similar major needs within home based care (Boryc et al 2010:488; Jooste, Chabeli & Springer 2009:4; Olenja 1999:188; Uys 2001:81; Thorne et al 2003:1344). Other critical needs expressed in the study and which could be considered universal from the studies cited above are: the need for care of orphaned children; ameliorating the fear of death; the need for the regular supply of medication; and provision of means of transport for accessing health services by service users and for accessing service users at home by care providers. These needs are often taken for granted when planning and designing health services, whereas they are essential for a functional health system and for meeting goals of both parties.

Qualitative findings of this study revealed the lack of financial resources for children’s school fees as a concern for many of the service users on C&HBC. Key informants also raised concerns that children were taking care of chronically ill adult relatives. These and other concerns indirectly expose the critical needs that these children in C&HBC supported homes have as a result of living with guardians suffering from chronic illness. The same situations apply in cases where the children are also suffering from chronic

illness. Studies carried out on children with chronic illnesses (Thomas 2012:26; Jackson 2012:8), confirm the impact of the complex health and social needs of children on their lives and on the lives of their families.

5.3.1.1 Nutritional needs

The nutritional and financial needs of service users had the highest ratings of needs identified in the study. Other studies assessing the needs of C&HBC studies in Africa also show similar results (Olenja 1999:198; Boryc et al 2010:488). Cannon (2008:8) suggests that poverty and lack of income are widely associated with susceptibility to disease and poor health outcomes. The researcher regards this aspect as the point of linkage between health and development and there is a need to address the two concurrently during programme design. According to Bowling (2009:66), “health care becomes a means of satisfying basic needs, since a healthy being can participate in social life”. Without their good health, people cannot go on with their daily living of meeting basic needs and a good health status cannot be met without income or other relevant resources. Those with high incomes enjoy good nutrition and relatively unrestricted access to health care. It is therefore no wonder that the findings in this study show poverty and lack of income and access to food as the main barriers to meeting the needs of the sick. This is similar to findings from a study carried out on “met and unmet palliative care needs of PLH and those with AIDS in Rwanda” (Uwimana & Struthers 2007:580-581).

The social, environmental and political determinants of health are factors to be considered in the future development and implementation of C&HBC programmes. The home based care programme has to constantly evolve in line with socio-political and economic contexts.

5.3.1.2 Physical care needs

Chronically ill people have diverse medical care needs. One of the needs identified, that is, pain and symptom management, is a critical component of care in chronic illness. Relief from negative symptoms and pain is a common need for a patient with chronic conditions. This was evident in this study as the need rated second in the study. Other HIV and AIDS studies (Uwimana & Struthers 2007:581) have corroborated this finding

and have revealed the unmet need for pain relief in service users with HIV and AIDS. Bodibe (2012) reports on a research which shows that South Africans living with HIV or AIDS in Limpopo, experience varied degrees of pain which go unreported. The writer further asserts that health workers do not have the skill and capacity to assess pain and treat it appropriately, since their training barely emphasises pain assessment and management. The situation and assumptions reported in the South African study corroborate the conclusions of this study, that as a result of the situation in Zimbabwe, service users are likely to be so overwhelmed with trying to meet their basic needs, such as food and rent, that worrying about pain becomes secondary in their daily lives.

Focus group discussions conducted during the research revealed that C&HBC service users usually experience neuropathic pain and other body pains without receiving adequate pain relief. The omission of inadequate symptom and pain management suggests that comprehensive palliative care is not fully provided in home based care. Home based care should prioritise this service if resources such as medicines, trained nurses and community workers, as well as transport, are made available to provide relief to service users in need of the service.

5.3.2 Meeting service users' needs

The needs of service users are evolving, especially with the introduction of new treatment regimens and the general awareness of human rights included in HIV and AIDS education. The scaling up of ART, which has occurred over the past few years, has had profound influence in shifting support required towards service users' and family needs and services. These have moved from basic nursing care of the terminally ill, to the need for support with drug-adherence; nutrition education; counselling and improving livelihood. Many of these needs have not been adequately met. New therapies and approaches for care and treatment for other chronic diseases are also in the process of being developed (Epping-Jordan 2005:88). Since needs are evolving and new technologies are also emerging, meeting service users' needs will ultimately have to keep up with new developments. Successes have been noted in other countries, where positive patients' outcomes have been realised through employing innovations such as the use of electronic patient records at the point of care, and the emphasis of multidisciplinary care (Edes 2010:33). The C&HBC strategy therefore needs to evolve within current health requirements, socio-political and economic contexts. These

sentiments were expressed during in-depth interviews by a key informant who strongly stated that “The C&HBC strategy was designed before ART. The strategy is outdated, seeing the needs that are there now are different – now service users need income-generating projects”.

In line with Imogene King’s conceptual framework (King 1981), meeting the needs of clients can be influenced by the efficiency or inefficiency of systems being implemented. It was evident from the clients’ needs revealed in this study that interventions such as provision of medication, health education and counselling relevant to chronic illness are provided more through the C&HBC system than through other health care services. Hence, these were no longer viewed as unmet needs by C&HBC service users, although health professionals felt that more could be done to improve coverage in those areas. This also shows the subjective nature of needs and expectations as described by Bowling (2009:51). The author states that expectations are generally difficult to understand, because they are based on values and beliefs of either the patient or the care provider. Information provided on health and health care may be misunderstood or misinterpreted by patients, resulting in a distortion of needs and expectations being raised by service users. For this reason, the health provider and service user are likely to view needs and care from different perspectives. The following paragraph provides an example of the different perspectives observed during the study.

The needs of service users identified from this study are dissimilar to those reported by Schoen et al (2009:5-10), from a study that the authors conducted in several developed countries. The needs identified in those studies were based on dissatisfaction with care, and related to efficiency of service provision, access, and coordination and safety experiences. Whereas in this and other studies in underdeveloped countries, there is less dissatisfaction with care and the considerable needs of a socio-economic nature that enhance access to adequate care, medical supplies, food and nutrition (Boryc et al 2010:488; Jooste et al 2009; Uwimana & Struthers 2007:584).

Further exploration of service users’ perceptions of services revealed that communities perceive that funders of C&HBC donate more resources to the programmes through the C&HBC-implementing organisations and community health workers than they eventually receive. This perception has led to seemingly excessive demands for support by service users and their care givers. Service users expressed distrust of community

workers, which could be a sign of the dependency of service users on handouts and free services or a misunderstanding of how donor support operates. It could also be a sign of poor communication between the organisations, community health workers and service users. This exemplifies Imogene King's personal and interpersonal and social systems-clash (Goodwin et al 2002:239-240), which can be resolved through open channels of communication, and joint decision-making. Since C&HBC is understood to be an extension of health services provided within the home environment away from hospital setting, service users expect the domestic environment to be similar to those in the health institution. This is what may bring about their expectation to be provided with beds, blankets, clothes and food, as happens to those admitted to hospitals. In another study (Byrne, Sims-Gould, Frazee & Martin-Matthews 2011:172) similar frustrations are described by service users where expectations of care and support are beyond what the organisation can provide, due to policies or diminished funding for specific items. Communication between service providers and service users on what constitutes C&HBC support and what can be obtained from other support networks is necessary.

The data from the study therefore positively suggests that meeting service users' health needs is about generating money through employment, and from income-generating activities, in order to increase their capacity to meet such essential needs as a balanced diet, medication, medical fees, and to provide for other family expenses such as school fees, shelter and clothes. This idea is noble, as it encourages independence and self-reliance in people with long-term illnesses, their families and their dependants.

5.3.3 Capacity of Community and Home Based Care programme to meet needs and goals of service users

The C&HBC programme has inadequate capacity to meet the needs of service users in the programme. This conclusion arises from the consideration of many factors, including constraints in human resources that the health sector has been experiencing over the past decade. Health institutions are understaffed, and the current personnel including community health workers are overloaded with a range of both nursing, administrative tasks and other duties. This is a constraint to the provision of patient-centred care and outreach activities, meant for those in C&HBC. Based on their concerns with effective provision of C&HBC, health professionals and community leaders interviewed as key

informants shared their hopes and expectations, as well as suggestions, to improve the C&HBC programme for attainment of the programme goals.

Hopes and expectations of key informants

- Delivery of intensified health education for service users and families living with chronic health conditions and enrolled in home based care programmes. Provision of training and education that benefits many people e.g. introduce C&HBC training in educational institutions because everyone needs the knowledge to care for the sick, especially children who find themselves caring for adults.
- Nurture closer links between the MoHCW and non-governmental organisations and encourage increased government participation in the implementation of C&HBC.
- Increase community participation by providing formal training to primary care givers; and increasing participation of men in C&HBC to ensure gender equality and support.
- Launch initiatives for service users to sustain the benefits received from care - such as supporting projects that secure their livelihoods and improve food security and adequate nutrition.
- Intensify home visits by nurses, through the provision of the means of transport and provide other medical resources. Intensify care and support for young people with chronic illnesses.
- Integrate provision of social services with community and home based care programmes.

The views above resonate with the concepts of Imogene King's Theory of Goal Attainment. King proposed that the social systems comprise people within the community (the health system and organisations included) with common goals and

interests, which in this case is quality health care resulting in an improved quality of life (Williams 2001:26). The structures of the social system should provide practical guidelines, resources and human capacity or skills for the attainment of these goals.

A study to investigate nurses' decisions about priorities in home based nursing care by Tønnessen, Nortvedt and Førde (2011:390) revealed that at times, health providers "ration home based care decisions" for patients based on their own or the system's challenges and apply those to prioritise activities. Challenges encountered may vary from too many patients to visit at a given time, to the need for cost efficiency. In such situations, service delivery is usually based on the availability of material, human or financial resources and not on service users' personal needs. Such practices are contrary to nursing ethics. In this study, similar sentiments were raised by health providers who often encountered challenges of transport, and inadequate human resources.

Client participation is also one of King's principles within the interpersonal system of interaction, whereby the client and care provider have distinct but complimentary roles (Goodwin et al 2011:239). Further, the client should be engaged in goal setting as a mutual partner, as well as in planning and decision-making concerning his or her care. The care provider should assume the role of a facilitator. Other writers (Mapanga and Mapanga 2004:278) also purport that "client participation provides empowerment in self-care and [participation] is one of the key outcomes for community health nursing practise for living with a chronic illness at home".

5.3.4 Effects of the programme on service users' needs and goals

According to Imogene King's transaction model; a transaction is made between a service user and care provider when both discuss (interaction) the goals to be attained, mutually agree on the goals and then plan to achieve those goals. Therefore, the perception on adequacy of care becomes based on whether service users' needs are met or not. Meeting service users' needs is also based on the quality of care; service users' independent functioning following treatment and rehabilitation; absence of or, reduced symptoms, and other positive outcomes. The study did not establish to what extent the transaction between care providers and service users takes place or extent to which needs assessments are made during service user recruitment. Community health

workers noted that one of their roles was to assess the needs of the family and service user before enrolment into C&HBC programme.

Service users' were generally satisfied (with the exception of a few areas mentioned earlier) with the level of care provided by care givers and health workers. Primary care givers also expressed satisfaction with the level of support received from the C&HBC programme, in terms of medical care. The health outcomes and subsequent improvement in the quality of life experienced, such as ability to walk, perform household chores and take care of a service user's own personal needs, were highlighted as positive effects of care and support. It is unclear whether this success was the result of ART, which was 'praised' throughout the study as having made a difference in the health status of those living with HIV and AIDS. When the issue was probed further with secondary care givers, they insisted that they have played a major role in the positive outcomes of service users through their contribution to C&HBC. They cited the roles they have played in health education, counselling and mobilising the community for early HIV testing, as well as treatment as the main contributing factors.

From the study it is possible to conclude that the outcomes of the programme are commendable, despite the many challenges experienced. This is in comparison to what the health situation of PLH and those with AIDS would have been in the absence of the C&HBC programme.

5.3.5 Enhancing community participation in improving health well-being

The Zimbabwe MoHCW (2009:31), Zimbabwe MoHCW & NAC (2011:52) and Zimbabwe MoHCW & NAC (2009b:24) emphasise the importance of community participation and involvement as an essential element to effectiveness of community health interventions. Consequently, structures that promote community participation were found to be in place, although their use and effectiveness varies from community to community.

The strategy of engaging community health workers in care and support of the chronically ill is an approach that enhances community participation in C&HBC. However, due to the shortage of human resources in the health sector, these community health workers come across situations and health conditions that they are ill-

equipped to deal with. For example, the study established that community health workers are unable to manage hypertension and acute diabetic symptoms. Many community health workers are not equipped with analgesics for pain management and relief due to the shortage of medicines and the inconsistent implementation of the policy on administering pain relief medicines, such as paracetamol, by care givers.

For these reasons, inadequate training and lack of resources to train and retrain all community health workers including primary care givers becomes an impediment to meeting service users' needs and achieving the goal of health-related quality of life. Intensive training of community health workers on broad health issues will not only assist in effective care and support, but will also ensure the sustainability of the C&HBC programme. A controversial challenge that is likely to arise is how to deal with the demands for regular employment and remuneration, when more responsibilities are added to the community health workers' roles. Their placement into the health system is an option when availability of financial resources is guaranteed.

The objective of ensuring community participation was strengthened by the formation of community peer support groups. These are made up of chronically ill people living in close proximity to one another. This structure is an innovative community response that provides an avenue for a service user participation and involvement in advocacy issues regarding care and support for the chronically ill. Stigma and discrimination of chronic illnesses, especially HIV and AIDS has, however, been seen as a constraint for people to enrol in these groups. By not joining the groups, they miss an opportunity for having their concerns heard, for personal growth, solidarity; problem solving and they are unable to benefit from resources channelled through these groups (data from key informants and service users).

Improvement and enhancement of community participation and capacity building are required for the success of community based programmes (Austin, McClelland & Gursansky 2006:164). According to Campbell and Cornish (2012:848), the missing element in community health programmes is the creation of a "transformative communication environment". This, according to the authors, is viewed as the key to effective community participation and empowerment. The writers describe transformative communication for marginalised groups as:

That which involves the development of critical understanding of the political and economic roots of their vulnerability to ill health and providing them with the confidence and strategies to address them. This is in contrast to technical communication which merely provides transfer of knowledge and skills such as awareness of HIV and AIDS and condom use (Campbell & Cornish 2012:848).

This commendable strategy centres upon communities learning in order to begin to lobby for the health needs and services that they are able to identify.

Stigma and discrimination were established to be widespread in urban areas, where there is overcrowding and life is about “survival of the fittest and healthiest”. There is a pervasive fear that disclosure of chronic illness might result in dismissal from jobs or eviction from rented homes. In rural areas, there is less stigma and discrimination and better coordination and collaboration within the communities. There is much more empathy and sense of care and concern among and within rural communities than in urban ones. This favourable situation in rural areas could be harnessed to support and intensify income generating activities for vulnerable households. The launch and support for income generating activities requires thorough feasibility studies in order to ensure sustainability. Communities in the study sites were aware of similar initiatives that had collapsed due to such challenges as low profit margins, lack of markets, and poor management among other things. Other studies in low and middle income countries (Wringe et al 2010:359) have reported similar challenges.

The concept of self-management or case management is described widely in available literature (Austin et al 2006:166; Swendeman, Ingram & Rotheram-Borus 2009:1323; McCullough 2009:125) as a scheme that empowers service users and enhances their choices, their decision-making and their participation in the health care process. From a study exploring the cost implications of service users’ choice of service delivery (case management approach), (McWilliam, Stewart, Vingilis, Ward-Griffi, Donner, Anderson, Hoch, Coyte & Browne 2007:176; Suter, Hennessey, Florez & Suter 2011:46) the authors concluded that clients choosing to direct their own care had lower home based care costs than with other approaches. This approach also enhanced service users’ participation in their own care. The options that clients choose from in McWilliam et al’s study were: (1) leaving the control of services and care to the system’s case manager,

(2) sharing control for care in partnership with a care giver, (3) service users' directing their own case management (McWilliam et al 2007:172). Self management approaches further demonstrate Imogene King's concept and theory of goal attainment (King 1980), which focuses on the client as the key participant in goal setting and planning of his/her own care. The client should take responsibility for decisions made with the support of health providers, the family and community systems. As further stated by Swendeman et al (2009:1323), clients with chronic conditions may require adhering to treatment regimens as well as lifestyle changing related behaviour in order to promote and maintain the health status that they aim for. These are responsibilities that only the client commits to in order to attain mutually set goals between client and the health provider.

5.4 CONCLUSION

The study has provided evidence from the experiences of people with long-term illnesses receiving C&HBC services through the national C&HBC programme in Zimbabwe. A satisfactory measure of needs was addressed by the programme with needs such as finance, food security, and pain-relief outstanding. Other needs related to support for children and "feeling useful" within the family, mostly by breadwinners or heads of households, also need to be addressed. Respondents reported that the C&HBC programme had generally improved their health status resulting in an enhanced quality of life.

CHAPTER 6

PROPOSED GUIDELINES FOR AN INTEGRATED APPROACH TO THE MITIGATION OF CHRONIC ILLNESSES

6.1 INTRODUCTION TO THE GUIDELINES

Changing medical professionalism to fit the changing health needs will not be easy. It will need strong leadership. But, if the medical world does not embark on this endeavour, good doctoring will become merely a bureaucratic and/or marketing exercise that obscures the ultimate goal of medicine which is to optimise the health of both individuals and the entire population.

(Plochg, Klazinga & Starfied 2009)

This chapter of the research study aims to provide an evidence-informed guideline for the development of integrated Community and Home Based Care (C&HBC) programmes primarily with social services, as well as with other health services. The guideline is a set of proposals that are based on key findings from the research that investigated the congruency of services that users need within the national home based care programme strategy and goals. The study identified the challenges of C&HBC which were also taken into account in the development of these guidelines and are listed in the box below.

6.1.1 Challenges of community and home based care

There are many challenges experienced in implementing C&HBC programmes in general. The following table highlights those challenges expressed by study participants. These challenges were established when respondents (service users, care givers health professionals and the community key informants) were asked to indicate the general problems faced by families of the chronically ill, that may affect health outcomes.

Table 6.1 Challenges of Community and Home Based Care and their effects on service users' needs and goals

Challenge raised by respondents	Effect of challenge on meeting service users' needs and goals
<ul style="list-style-type: none"> Inability of service users to buy prescribed drugs that is not available or are out of stock at health facilities, due to lack of financial resources. 	<ul style="list-style-type: none"> The priority need for service users is to have medication for treatment. Nurses can only meet the health needs when financial and other resources are available. Service users fail to adhere to drug regimens leading to side effects and complications.
<ul style="list-style-type: none"> Shortage of home based care supplies (kits). (These are handed out to service users by community health workers, collected from health facilities). 	<ul style="list-style-type: none"> These kits are essential medical items required by bedridden and terminally ill patients.
<ul style="list-style-type: none"> Diverse social situations, beliefs and practices in service users' homes. Abandonment and neglect of service users with chronic illnesses by relatives. 	<ul style="list-style-type: none"> Stigma and discrimination experienced by service users prevents access to care and support. Service users who are renting houses are known to refuse to disclose their addresses and miss out on visits by health providers at home out of fear that the landlord will evict them from the premises once a stigmatised condition is exposed.
<ul style="list-style-type: none"> Non-availability of financial resources, poverty and lack of livelihoods among service users and their families especially if the service is a breadwinner. 	<ul style="list-style-type: none"> Families cannot afford diagnostic tests, transport fares to access health services, medicines, food and others items of comfort.
<ul style="list-style-type: none"> Lack of food security especially in homes with the elderly and also in child-headed homes. When WFP food handouts run out or when patients are discharged from the food programme, they look for food assistance at clinics. 	<ul style="list-style-type: none"> Food provides nutrition for the body and is required to build the immune system during illness. Some medicines cannot be taken on an empty stomach. Food is a basic and essential need.
<ul style="list-style-type: none"> Long distances between health facilities and the community. Lack of transport facilities for service users to visit clinics and for health professionals to visit homes. 	<ul style="list-style-type: none"> Health professionals provide proficient assessments of service users' needs and should be in the forefront of conducting the assessments. Service users' needs such as, strong analgesics for palliative care can only be

Challenge raised by respondents	Effect of challenge on meeting service users' needs and goals
	<p>provided by professional nursing staff.</p> <ul style="list-style-type: none"> • Easy access to health facilities required for emergencies.
<ul style="list-style-type: none"> • Many service users are cared for by children and youth who lack skills to handle certain illnesses, such as mental illness and other conditions. • Lack of knowledge by primary care givers of nursing care skills for specific conditions. • Lack of reliable and appropriate referral organisations in some programme areas. 	<ul style="list-style-type: none"> • Children and young people cannot provide for adult needs efficiently. • Only people skilled in a particular field/area can provide appropriate care. • Since health facilities cannot meet the social needs of service users they refer to NGOs in the area. However, the needs are usually not met because the NGOs have their own mandates, and thus cannot attend to the real and practical needs of the community and the service users.

Many of the challenges disclosed were found to be consistent with those encountered during review of other literature from Zimbabwe and elsewhere in Africa. For example, the lack of integration of HIV and AIDS programmes for strengthening the health system in Zimbabwe in order to address multiple patient needs across a continuum of care and to meet goals, was also expressed by Chevo and Bhatasara (2012:10) in a study on implications of HIV and AIDS programmes on the health system in Zimbabwe.

Further analysis of the above challenges highlights them as key determinants of success in meeting needs and goals of service users on home based care.

6.1.2 What is the meaning of an integrated approach to health services?

Literature suggests that there is no clear definition of this concept/term, and many definitions exist based on people's understanding of the term (Robertson 2011:6; WHO 2008a). According to the WHO (2008a), integrated service delivery is "the organisation and management of health services so that people get the care they need when they need it, and in ways that are user-friendly, achieve the desired results and provide value for money". It is clear from this definition that integration is not an end in itself, but rather a means to an end (WHO 2008a). Robertson (2011:6) further describes integration as any or a combination of some of the following:

- Health and social services delivered by a single organisation
- Joint delivery of health and social services by more than one organisation
- Links between primary and secondary health care
- Joining care at different levels within a single sector e.g. mental health services
- Joining prevention and treatment services
- Services are jointly commissioned and/or funded
- Services are delivered by multi-disciplinary teams in which team members are employed by more than one organisation
- Services are delivered by multi-disciplinary teams in which members are employed by the same organisation

6.3 RATIONALE FOR AN INTEGRATED APPROACH IN COMMUNITY AND HOME BASED CARE

The shift towards integrated services for care of the chronically ill is about developing and implementing health care strategies that result in improved health outcomes and quality of life. This is confirmed in evidence suggesting that the tackling of chronic diseases requires more than the medical management of symptoms, but that it extends to the empowerment of patients and to addressing the barriers to healthy lifestyles which require harmonised interventions (DeHaven & Gimpel 2007:529; Van Weel, De Maeseneer & Roberts 2008).

C&HBC has been largely implemented in a setting plagued by a depressed economic environment that is exacerbated by policy inconsistencies. This has exacerbated food insecurity, poor nutrition and poverty and resulted in an increase in the disease burden, especially with chronic illnesses such as TB, HIV and AIDS, cancer, diabetes and respiratory problems. Chronic conditions have further complicated and worsened the lives of those affected.

In most cases, chronic conditions do not receive the requisite attention they deserve due to a multiplicity of individual and structural factors. The poor health infrastructure, human resource shortages, and the lack of coordinated services are constraints to quality and efficient health care. Service users and families are adversely affected by long-term illness, resulting in reduced capacity to mobilise for the essentials of life.

Given the limitations stated above, it is anticipated that an integrated approach to C&HBC may ensure provision of services in more systemic and less cumbersome ways, by the few health practitioners available. This will only happen when health personnel are provided with the necessary skills, equipment, motivation and other logistic support. Where integrated services have been reviewed, findings have shown that both nurses and service users were satisfied and empowered through the implementation of integrated services (DeBrew & Lutz 2010:66). MacAdam (2008:24) also found indications that some models of integrated health and social care for the elderly with chronic illnesses resulted in improved outcomes, as well as cost-effectiveness.

Reiterating the above issues, Epping-Jordan, Pruitt, Bengoa and Wagner (2004:299) suggests that innovative practices are needed in order to address the complex and long-term health needs of chronic conditions. It is evident even in this study that chronic illnesses place a huge demand for resources on ill people and their families. These illnesses also increase demands in the health sector and the nation as a whole. Development-oriented strategies are also necessary to mitigate the plight of those affected by the interaction of HIV and AIDS, health and socio-economic challenges. Epping-Jordan and other scholars, Loewenson, Hadingham and Whiteside (2009:1038) further propose implementing population-based-strategies (with relevant interventions), targeting a defined population rather than individual patients. This ensures wider access, and increases cost effectiveness for programmes. However, implementing integrated health/C&HBC and social services raises challenges, which will be listed later in the guidelines mentioned here.

As suggested by Kodner (2009:12), “integration is essential for sustaining health systems and programmes in order to meet changing service users’ needs and demands”. As the world economic crisis persists, and given the limited funding available in developing countries, there is need to utilise available resources in a thoughtful manner. Integration could be one of the strategies for ensuring that health care goals are accomplished as expected.

6.4 SCOPE AND PURPOSE

Integration of C&HBC with social services and other preventive and control programmes within the existing public health system, will be enhanced through a framework that outlines key focal areas for implementation and adoption by all stakeholders. Direction is sought from the World Health Organisation Action Plan for the prevention and control of non-communicable diseases (WHO 2008d:4). The strategies suggested are also aligned with the WHO's review of innovative best practice and affordable health care models (Epping-Jordan 2001:947).

Evidence-based guidelines generally play a role in informing policy-makers and programme planners of best practice to improve or change their care practice, to set standards and to ensure safe and quality care. However, dissemination of guidelines and their implementation is dependent on the 'national authorities' enthusiasm to act on these recommendations, as well as financial barriers to initiate new ideas (Fretheim, Schünemann & Oxman 2006). There is therefore a need for strong lobbying by health authorities at all levels to ensure the adaptation and implementation of such guidelines.

These guidelines refer specifically to Zimbabwe service delivery, and recommend strategies and activities that can be undertaken in the local context. The guidelines should be used as a base for planning and reviewing quality integrated C&HBC programmes within the framework of the overall health system. Although the guidelines are based on C&HBC and interventions for chronic communicable and non-communicable diseases, it has been designed for adaptation within the overall health care delivery system.

These suggestions are by no means exhaustive and organisations or institutions should not restrict themselves to these strategies but are to use them as a catalyst for innovation.

More specifically the guideline will provide some background and a necessary challenge to health care organisations for the identification of areas that need improvement in C&HBC nationwide, which will motivate them to accomplish more, as well as a challenge to policy makers to develop policies based on the proposed reforms and ensure that they are implemented.

6.5 GUIDING PRINCIPLES

- Adherence to the Primary Health Care Strategy. According to Plochg et al (2009), primary health care is “an indispensable feature of a well performing health system in the twenty first century”.
- The chronically-ill patient/client/service user should be the centre of focus.
- Equitable access to health services and social services should be available for all socio-economic groups.
- Collaboration and systematic coordination of activities and programmes that enhance health outcomes should be made through a multidisciplinary response.
- Accountability should be made of service provider to service users, by ensuring the provision of resources and responsible actions by service users.
- Service users should be empowered to manage self-care, raise the profile of chronic diseases, be involved in designing and evaluating programmes, and hold authorities accountable for quality and equitable service provision.
- A partnership approach that enhances effective communication, sharing and learning among stakeholders should be formed.
- A family centred and comprehensive approach should be taken “that addresses the needs of both adults and children in a family and attempts to meet their health and social care needs, either directly or indirectly, through strategic partnerships and/or linkages and referrals with other service providers” (Kent, Lorpenda & Fay 2012:7)
- Sustainable interventions must be at the forefront of the establishment of programmes that mitigate the dire situations faced by chronically ill people.
- Provision should be made of proactive care that anticipate patients’ needs, rather than depending on symptoms presented by the patient.

6.6 CONTEXT AND OVERVIEW OF CHRONIC HEALTH CONDITIONS

As stated earlier in the main report, a significant proportion of poor and disadvantaged people have not been spared from the chronic disease burden in Zimbabwe. Prevention, treatment and mitigation strategies need to be intensified. This cannot be achieved, however, if the status quo in health delivery is maintained. New evidence-

based strategies are required and government should be willing to undertake reforms in the health system and related delivery services.

There is growing evidence that management of chronic diseases is creating serious challenges to many health systems (Glasgow, Durand-Zaleski, Chan & Rubiano 2008:85) and that one of the strategies sought to provide effective care of these conditions is the improved integration of care and support.

A widely recommended strategy for mitigating the impact of chronic illness on individuals, communities and health systems is integration of health and social systems, in order to ensure that all services required are accessed by those who require them. (Shigayeva, Atun, McKee & Coker 2010:i8; Mayosi et al 2009:943). The authors further suggest that integration improves the performance of health systems, since it removes duplication and ensures patient satisfaction with services. There is evidence from home health care studies (Epping-Jordan 2005:720; Glasgow et al 2008:72) including this one, that integration of these two systems is required.

A distinction is made by Glasgow et al (2008:71) between the types and levels of integration based on context. These are described below.

6.7 INTEGRATION OF SERVICES

According to Kodner (2009:7), “integration is designed to create coherence and synergy between various parts of the health care enterprise, in order to enhance system efficiency and quality of care, quality of life and consumer satisfaction, especially for complex and multi-problem patients or clients”, such as those with chronic conditions. Integration is also viewed as “an interdisciplinary, inter-professional, non-hierarchical blending of approaches” that provide continuum of patient/client-centred care. It employs a collaborative approach, based on mutual understanding and a shared vision (Soklaridis 2008:20).

In a study on integrated health care in specific setting, Soklaridis (2008:192) points out the importance of developing a mutual understanding on the concept of integration between by all partners involved, due to diverse philosophies of stakeholders regarding

integration. Having a shared vision is necessary, particularly in this instance, where several disciplines are expected to agree on goals and to work collaboratively.

Another level of integration is presented by Van Weel et al (2008:872) who suggest that:

Integration of community-oriented primary care and personal care are essential for addressing individual needs within the context of an entire targeted population's needs. When structural issues that affect the entire community (such as improvement of environmental health conditions) are addressed, health services become more congruent with community and individual needs.

Kodner (2009:7) further asserts that integration can focus on either entire communities; targeted populations (irrespective of health status); vulnerable groups, or patients with specific conditions such as chronic illnesses. Integration is broad and of various types (Kodner 2009:7; Glasgow et al 2008:71). The types and scope of integration suggested by Konder are presented below:

- **Functional integration:** the extent to which coordination of key support functions such as management of finances and human resources, strategic planning and information management occurs across all units
- **Organisational integration:** relationships and networks between health care organisations and institutions
- **Professional integration:** provider relationships within and between institutions and organisations
- **Service integration:** coordination of services and integration of care across disciplines, and units
- **Normative integration:** having a shared mission, work values and organisational culture
- **Systemic integration:** alignment of policies and incentives at organisational level
- **The breath of integration:** the range of health care services provided. Horizontal integration takes place between organisations or organisational units that are on the same level in the delivery of health care or have the same status; vertical integration brings together organisations at different levels of a hierarchical structure.

- **The degree of integration:** ranging from full integration that is, the integrated organisation is responsible for the full continuum of care (including financing), to collaboration, which refers to separate structures where organisations retain their own service responsibility and funding criteria.

At a presentation during a symposium, Leutz (1999) differentiated the levels in integration from his study on “Five Laws for Integrating Medical and Social Services: Lessons from the United States and the United Kingdom”, as follows:

- **Linkage** allows individuals with mild to moderate health care needs to be cared for in systems that serve the whole population without requiring any special arrangements. Proactively give service users accurate information about how the system works and how to access benefits and services.
- **Coordination** requires that explicit structures be put in place to coordinate care across acute and other health care sectors. While coordination is a more structured form of integration than linkage, it still operates through separate structures of current systems. It helps service users who have moderately complex needs to navigate the system, coordinate care and share information routinely.
- **Full integration** creates new programmes or entities where resources from multiple systems are pooled. For those with complex needs and who can't manage, create special integrated sectors where acute and long-term care providers and managers work in teams. The figure below shows the levels of integration according to user needs.

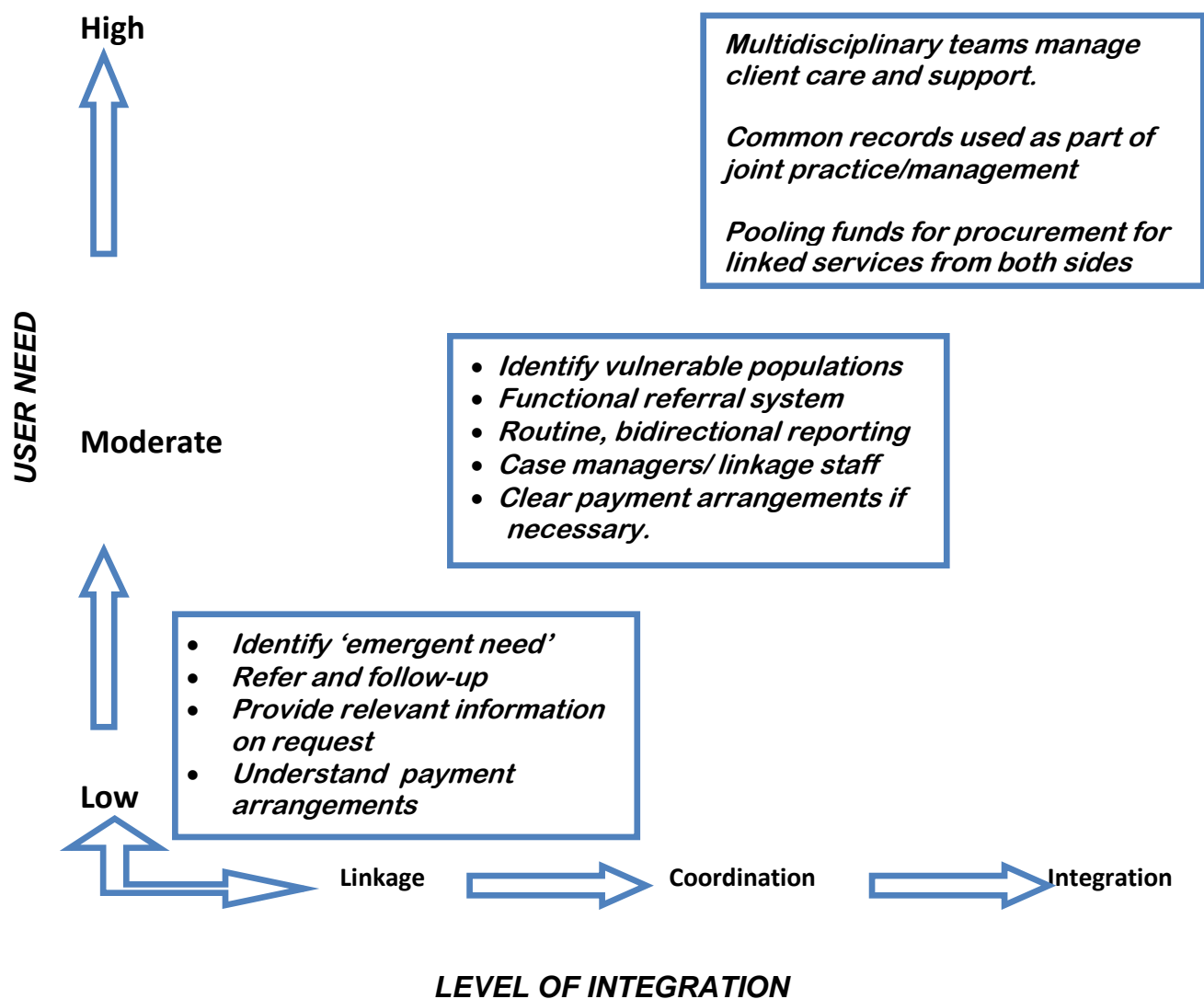


Figure 6.1 Levels of integration and user need
(Adapted from Leutz 1999)

The diagram above indicates that not all clients/service users or communities have the same needs or will require the same level of support. Therefore, their needs can be categorised into low, moderate and high in order to establish the level of support that will be required.

6.8 DEFINING KEY TERMS

There are a number of terms that are repeatedly used in these guidelines and for the purpose of clarity and accuracy their meanings are presented below:

Comprehensive: means that each of the demonstration projects integrates some medical, social and supportive services.

Coordinated: means that each project uses some method for example, case management or direct service delivery to bring together services in a manner that best meets the needs of an individual.

Community-based: means that the projects focus on community services as a means of delaying or reducing clients' stay in institutions.

System: refers to the deliberate attempt on the part of each project to establish procedures for assessment, care coordination and reimbursement that integrate the diverse services needed by the patient into a more rational system.

Long-term care: means that the projects focus on those individuals who have one or more impairments that put them in need of continuing or chronic health care and supportive services (Zawadski 1984:23).

6.9 KEY ELEMENTS OF FOCUS AND IMPLEMENTATION TO IMPROVE CARE AND OUTCOMES FOR CHRONIC CONDITIONS

The following section provides what can be termed the methods or tools for use in the process of integrating care and support for the long-term care of chronic conditions with social services. The approaches can be adapted for use by organisations, health institutions, home care establishments and other relevant entities. They provide a guide for administration and management, service delivery, information management and monitoring and evaluation of integration.

Integration of services can occur within each health institution, between health and non-health institutions, and within community based health services. Different methods of integration have been proposed. One method is the structural integration of separate services within one organisation. However, in order to provide quality integrated services, reforms have to occur from the health systems level to the organisational level. It should be noted that appropriate infrastructure and human resource capacity building will be required.

Note: Integration should aim at providing quality affordable care, enhance efficiency and ensure positive outcomes based on patients' health needs.

6.10 SERVICE DELIVERY

The principles of family-centred care should apply regardless of where nursing care takes place, that is, in the home or in a health institution. The individual, family and local population should be brought into the care process at all times. The system of health care should demonstrate certain standards and practices. The health professionals involved should also adhere to standards relevant to the new order of integrated care. Health professionals tend to underestimate the importance of social systems and their influence on patients care and support (Plochg et al 2009). An integrated service ought to pay particular attention to some of the following points.

6.10.1 Provide comprehensive services across the care continuum

Through:

- Cooperation and collaboration between health and social care organisations.
- Establishment population-based requirements and patient needs through needs assessment surveys and there should be focus on implementation in a defined population.
- Ensuring a patient and family-centred philosophy that focuses on social protection.
- Promotion of patient engagement and participation.
- Implementation of appropriate interventions for chronic illnesses and disease management.

6.10.2 Competencies required of health professionals to ensure quality of care and service delivery

The following community health nursing competencies can be adapted to all types of nursing situations (DeBrew & Lutz 2010:65):

- Creating collaborative relationships between service user and care provider to set goals and priorities and develop treatment plans.
- Documenting care according to professional standards.
- Assessing the holistic health status of clients including risk assessment.
- Valuing diversity.
- Practicing cultural awareness and striving for cultural competency.
- Including the client/service user in health care decisions/partnership and mutuality.
- Assessing barriers to prescribed care.
- Communicating effectively in order to:
 - Interpret health-related information to service users and families especially on discharge from hospital and at home.
 - Provide appropriate health education and empower service users to improve health and healthy living standards.
 - Link service users to needed resources and collaborating with inter-professionals to meet care needs. Link health care to social services in the community.
 - Be a service user's advocate.
- Assisting service users in developing skills for self-support and to manage their own conditions as much as possible.
- Conducting outreach and follow up care for service users in a programme.

6.10.3 Integration with social and other related services in Community and Home Based Care for chronically ill people

The table that follows lists some of the potential and targeted partnerships and their value in the support of an integrated response to meet service users' needs.

Table 6.2 Support services of the integration process

Partner	Services
Health facilities	Referral: for emergency care, professional advice, counselling and acute care services. Diagnostic services and treatment of complicated and serious conditions.
Non-governmental organisations implementing	Humanitarian support. These organisations have diverse mandates, therefore programme planners have to identify what each organisation offers and refer service users appropriately. Areas of potential linkage for social support are: food support; seed inputs for nutrition gardening; support with start-up for income generating projects; cash transfers; microfinance projects; and OVC care and support.
Multi-national organisations	Funding; technical support; humanitarian assistance such as food aid; cash transfers; orphan support; and sustainable livelihoods support.
Agriculture institutions	Providing seed and other inputs for nutrition gardens; technical support in crop production; training in project management; food processing and marketing skills.
Hospices	Offering family-centred palliative care including: physical; psychological; emotional; spiritual and bereavement care. Symptom and pain assessment and management. Goals of care are discussed and agreed between patient and health provider.
Rehabilitation services	Providing individualised services based on service users' needs such as occupational therapy, physical therapy, and speech-language therapy; assessments; counselling and guidance; capacity building in specific areas. Job development and placement.
Private sector	Availing funding through corporate social responsibility projects; skills transfer and technical support. Developing workplace policies that are supportive of those with chronic illnesses.
Community support groups	Provide opportunities to learn how other people cope with similar and varied problems. Members share personal experiences and are empathetic; are keen to establish social links and solve their common problems. Funding from donors for income-generating activities for people living with chronic diseases is channelled through these groups.

6.11 FACTORS THAT ENHANCE INTEGRATION AT INSTITUTIONAL OR ORGANISATIONAL LEVELS

Organisations or institutions have the responsibility to make integration with social services work and should lead through commitment to a functional system. The governance structures should promote strong, focused, management represented by an inclusive executive board membership from all stakeholder groups. The organisational structure should promote coordination across sectors and levels of health care. More specifically the management should:

- Lobby for funding for chronic care in view of the debilitating nature of the conditions that often result in loss of livelihoods.
- Implement policies that ensure access to services for all, remembering that services have a responsibility to ensure the identification and mitigation of constraints to social services and health access. For example, they could lobby for the provision of subsidies for those who cannot afford health insurance for chronic illnesses.
- Ensure meeting of health needs and services through the implementation of effective interventions that are relevant to local communities.
- Develop functional systems that foster responsibility and accountability for service delivery that is of high standard and meets the needs of service users.
- Improve transportation and communication services to support logistics, supervision and timely referrals.
- Strengthen the referral systems at all levels of the multidisciplinary system.
- Promote continuity and coordination of activities.

6.11.1 Human resources at organisation/institution levels

- The workforce should be appropriately trained and motivated to embrace the value of working jointly with organisations and people that may not necessarily be trained in the health field.
- Organise, train and equip personnel with relevant knowledge and skills on social determinants of health, concepts and the processes of integrated services.

- Sufficiently develop a resource integration strategy at community level by providing training and follow up support to family and community care givers.

6.11.2 Financial resources at national and organisation/institution levels

According to Robertson (2011:3), “Integration is not a quick or cheap option” It aims to achieve the following:

- Ensure consistent and adequate financing and allocate adequate financial resources to sustain the new integrated system (the development of new structures and skills), and for sustainable change.
- Reorganise health care financing to facilitate and support evidence informed care initiatives.
- Pool funding at various levels of integration where necessary. Align service funding to ensure equitable distribution for different interventions or levels of service.
- Lobby for the establishment of locally sponsored or government sponsored health insurance schemes for vulnerable-chronically ill people. An efficient and robust system of managing the insurance schemes should be in place.
- Funding mechanisms should motivate and promote inter-professional teamwork and health promotion within organisational personnel. This will further promote a stronger knowledge base and common understanding of issues.

6.11.3 Basic ideas of a locally-sponsored government health insurance scheme

The following segment provides an example and basic ideas of how a locally-sponsored government health insurance scheme could be planned.

Indian experiences with government-sponsored health insurance

- The government-sponsored health insurance aims to provide financial protection to the poor against catastrophic health shocks. These are often those with chronic illnesses and living below the poverty datum line. “Catastrophic” health shocks are defined in terms of inpatient care, which is likely to be serious and

requires large sums of money for admission fees. Ambulatory care is largely uncovered except for limited coverage as part of an inpatient episode (La Forgia & Nagpal 2012:47).

- A package rate is a simplified case rate consisting of a single fee or close-ended payment for a set of inputs and services for a specific and predefined treatment or procedure. Package rates offer several advantages. They are easy to administer, are less complicated or subjective than an open ended fee-for-service arrangement, and, in principle, can contain costs if the rates are set at or near costs.
- To be effective, the health insurance should make available to beneficiaries, the providers who possess the knowledge, processes, and capacity to provide quality care efficiently. Insurance presents an opportunity to raise service standards because, as direct purchasers of health care, insurers can use their financial leverage to improve quality such as requiring the reporting of data on outcomes and quality processes (La Forgia & Nagpal 2012:70).
- The scheme uses intermediary agencies, such as commercial insurers and third-party administrators, to perform most managerial functions on their behalf since they have the technological acumen, management experience, professional manpower available for performing functions such as provider network management, administration of preauthorisation processes, claim processing, and information management (La Forgia & Nagpal 2012:93)
- The scheme has its challenges, but since it is taken as a learning process, these challenges are addressed as soon as realised as part of the process of growth.

This initiative could be adapted to suit service users enrolled in community and home based care.

(Adapted from Forgia & Nagpal 2012)

6.12 FUNCTIONS AT POLICY MAKING LEVEL

- Assess and monitor (through commissioned research) the public-health burden imposed by chronic diseases and their determinants, with special reference to poor and marginalised population groups.
- Promote integrated policies by ensuring that policy development involves all relevant government departments and other stakeholders, thereby ensuring that public health issues receive appropriate cross-sectoral responses.
- Incorporate the prevention and mitigation of chronic diseases explicitly in poverty-reduction strategies and in relevant social and economic policies.
- Promote the implementation of health programmes that address the social determinants of chronic diseases. Also include programmes which mitigate poverty and address sustainable livelihoods.
- Prepare national plans with the active involvement of sectors outside health.
- Establish an adequately-resourced chronic disease and health promotion unit within the Ministry of Health and Child Welfare.
- Strengthen partnerships. Since the major determinants of chronic diseases lie outside the health sector, collaborative efforts and partnerships should be intersectoral to ensure positive impact on health outcomes in respect of care for chronic diseases.
- Continue the emphasis on Primary Health care, which characterises integrated health service delivery.

6.13 STRATEGIC PARTNERSHIPS IN ZIMBABWE

The Zimbabwe MoHCW has been strengthening sector level networks, linkages, partnerships and coordination over the last few years. Coordination structures are developed from district to provincial level. However, coordination remains weak between the sectors and more work needs to be done (Zimbabwe MoHCW & NAC 2011:100; Mazzeo & Makonese 2009:452). Poor collaboration has caused fragmentation in service provision, which fails to attend to the interests of the service user. Structures such as the Provincial AIDS Action Committees (PAACs), District AIDS Action Committees (DAACs) and Ward AIDS Action Committees (WAACs) are key coordination structures developed as part of the national response to the HIV and AIDS

epidemic. “Mainly the PAACs and DAACs have remained functional” (Zimbabwe MoHCW & NAC 2011:100).

To support the C&HBC programme response, partnerships with civil society and social services are required. The national HIV and AIDS strategic plan (Zimbabwe MoHCW & NAC 2011:120) emphasises that every ministry has a role in the HIV and AIDS response. Fifteen ministries were singled out in the ZNASP as being critical to the attainment of outcomes and impact of the national strategy. The list shown in these guidelines (with adaptation) is that of selected government ministries that have a direct role in C&HBC response, and should therefore be engaged.

6.13.1 Government ministries that have a direct role in Community and Home Based Care integrated services

1. ***Ministry of Health and Child Welfare (MoHCW):*** The Ministry of Health plays a regulatory role for matters relating to both public health and primary health care. It is the lead technical agency responsible for the provision of HIV prevention, treatment and care services in the country. The health sector has effectively mainstreamed HIV into its core business. The National AIDS and TB Control Programme in the MoHCW effectively coordinate the national HIV response within the public, private, and NGO/FBO health sectors.
2. ***Ministry of Education, Sport and Culture (MoESC):*** The Ministry responsible for primary and secondary education, sport and culture in the country. MoESC is a critical ministry in the response to the epidemic, because reduction of HIV incidence is largely dependent on targeting young people both in and out of school by catching them young through the education sector, through provision of education, values, norms and behaviours that are amenable to changing the course of the epidemic.
3. ***Ministry of Finance (MoF):*** The Ministry can mitigate the impact of poverty through initiating pro-poor policies aimed at poverty-reduction that can benefit vulnerable populations, PLH and those with AIDS and Orphans and Vulnerable Children (OVC).

4. ***Ministry of Information Media, Information and Publicity (MoMIP):*** The Ministry is the core agency responsible for disseminating and transmitting critical information on government priorities to the general public. The sector's role and engagement in ZNASP will involve dissemination of HIV-prevention education, behaviour change communication and linking people-in-need to critical HIV and AIDS services.
5. ***Ministry of Local Government, Rural and Urban Development:*** This Ministry is responsible for local government and oversees administration of municipalities, districts and provinces of Zimbabwe. The ministry may be approached for allocation of land and relevant licenses for service users seeking to embark on income-generating activities.
6. ***Ministry of Gender and Women Empowerment.*** Available evidence indicates that women carry the burden of care and also constitute the larger population in the country. Hence, the ministry is a core partner in the response to the epidemic in ensuring that the policy and regulatory framework that heightens women and girls risk vulnerability to HIV infection and other chronic diseases is addressed.
7. ***Ministry of Youth, Development and Employment Creation:*** Youth are the backbone of society in terms of reproductive and economic productivity, yet their livelihoods are threatened by the HIV epidemic. Youth are also involved in caring for the sick in C&HBC.
8. ***Ministry of Agriculture:*** The ministry provides the closest presence and link with the most remote, hard-to-reach populations within the country's local communities. Nutrition plays a pivotal role in the management of HIV. Communities survive on subsistence farming and the ministry can therefore provide capacity for small rural farmers to produce increased and improved quality crop yields.
9. ***Ministry of Public Service, Labour and Social Services (MoLSS):*** The ministry's core business is to monitor child-related activities, both within the school and home environment. Its other core mandate is to ensure that employees and employers observe and abide by the labour regulations act.

Plays a critical role in mitigating the impact of HIV and AIDS on OVC through further partnerships i.e. UNICEF. Also assists with letters to waive user-fees for health care for those who cannot afford and provides limited amounts of food support.

10. ***Ministry of Small and Medium Enterprise Development:*** This ministry has a role in ensuring that C&HBC clients and their families are involved in sustainable IGA for livelihoods.

6.14 SERVICE USER AND COMMUNITY PARTICIPATION AND EMPOWERMENT

Service users have a right and a responsibility to be involved in the planning, implementation, monitoring and evaluation of programmes addressing their health or other related needs. In theory this is easier than when put into practice. There is growing recognition (Ratna & Rifkin 2007:519; Balding & Maddock 2006:33) that “service users have a potential to influence their own health outcomes if they are actively involved in setting goals, in shared decision-making about their treatments, and if they are provided with quality information and the opportunity to participate in the evaluation of the care they receive”. This involvement leads to the empowerment of service users, which is one of the sustainable health outcomes.

There are many ways in which service users and their families can be involved in care and treatment, as shown in the “CHOICE” (Capacity Building; Human Rights; Organisational Sustainability; Institutional Accountability; Contribution and Enabling Environment) framework developed by Rifkin (2003:172) and summarised by Ratna and Rifkin (2007:520). The tool (shown below) highlights six areas that result in positive outcomes of equity and empowerment if used in health programmes design and implementation. The tool can also be used for programme evaluation.

Table 6.3 The CHOICE framework

C	Capacity building is defined as a process by which people gain skills and knowledge for the improved lives of beneficiaries. It is beneficiaries applying new skills to the political, social and economic environment. Capacity building stresses the importance of local knowledge and is an important step towards empowerment.
H	Human rights are a moral and ethical concept that allows people to better sustain their well-being when they can participate in decisions about their own lives. It allows people to take action.
O	Organisational sustainability ensures sustainable health gains, which depend on long-term organisational structures. Key factors are financial resources to maintain structures. Sustainability is therefore essential to equity. Empowerment is a key concept to ensure sustainability because it contributes to ownership of the programme by beneficiaries.
I	Institutional accountability – by developing accountable relationships with health service providers, the community has the capacity to address equity issues. Accountable and transparent mechanisms that respond to community needs are essential.
C	Contribution – contributions can enhance resource mobilisation, though stakeholders are often given little choice about that to which they contribute. Contributions can be in the form of time and energy to support in project initiation, implementation and monitoring and evaluation, which can improve the responsiveness and quality of services provided.
E	Enabling environment – this is created through changes in perceptions, attitudes and behaviours of those in authority. Information availability and ownership of information are essential, as they help lay people to partner with professionals.

(Adapted from Rifkin 2003:172)

6.15 INFORMATION MANAGEMENT AND DISSEMINATION

A coordinated information flow process between service providers is critical for patients with chronic illnesses, especially those with multiple conditions. Such patients tend to move between many service providers for treatment of multiple symptoms and complications. Coordinated care and systematic information provision of service users avoids duplication of services, such as diagnostic services and treatment. Other critical areas are as follows:

- Establishment of state-of-the-art information systems to collect, store, track and report activities across the continuum of care.
- Training of personnel in data retrieval, analysis and use.

- Enhancement of communication and flow of knowledge and information between patients and service providers and across providers. Use of electronic information systems and tele-health technologies with patients and other service providers should be encouraged where possible.
- Usage of information technology (e-health), with systems designed to support the integrated approach to care and support. Design flexibility ought to allow for the incorporation of changes in future.

6.16 MONITORING AND EVALUATION OF SERVICES

Monitoring and evaluating the quality of services and outcomes of the integrated response ought to be undertaken by developing core evaluation indicators of the outcomes that integrated services have on service users and their families and care givers. Other areas to be evaluated are: assessing progress and changes in services; cost-effectiveness of the system approaches to integrated services and changes in processes and protocols, to improve the integration of services. Monitoring and evaluation can be enhanced through the implementation of a comprehensible data management system and its utilisation.

6.16.1 Benefits of monitoring and evaluation

- Monitoring and evaluation of chronic diseases and their determinants can provide the foundation for advocacy in evidence-informed decision-making, policy development and action.
- Assessment will offer an opportunity to learn from experiences in order to take corrective measures where actions have not been effective.
- Reorienting parts of the plan in response to unforeseen challenges and issues can be effected as and when deemed necessary.

In summary, being aware of and removing barriers to integration should be a function of organisations aiming for success through integration. The following is a summary of enablers and barriers to integration provided by Robertson (2011:30):

Table 6.4 Enablers and barriers to integration

Enablers	Barriers
Supportive legislative/policy environment	Inconsistent or rapidly changing policies/legislation
Combined health and social care organisations	Diverse organisational cultures
Pooled resources	Inter-professional rivalries
Co-location of organisations/institutions	Medical dominance
Single employer for health and social care staff	Separate IT systems that are not coordinated.
Up-to-date, accessible patient information	Diverse management arrangements
Robust Information Technology (IT) which allow different sectors/organisations to communicate easily	Separate budgets
Meaningful inter-professional collaboration	Segregated training

Source: Robertson, H 2011:29

Several intermediate benefits are likely to be claimed from integration of social services with home based care. However, impact evaluations of such services need to be done in order to show evidence of the long-term benefits to health status and quality of life of service users.

6.17 CONCLUDING QUOTES

The AIDS response taught us that efforts to address a pandemic are incremental and take time. We must have patience. And we need to be both opportunistic and strategic to design an NCD response that is commensurate with the scale of the problem (Peter Piot-As Executive Director of UNAIDS from 1994 to 2008).

We have gone beyond the intuitive belief that integration is a good thing that can ultimately lead to better health services and outcomes. Experience tells us that integrated care does work, and that there are a number of basic building blocks and lessons that are responsible. To sum up, whatever the dilemmas and unknowns and the circumstances to support it, we can bring the many benefits of integration to inherent in integrated care, it is nonetheless still possible to make it happen. It may not be easy, but with clear vision, the right combination of strategies and resources, populations with the greatest need, as well as to the health system at large (Kodner 2009:13).

CHAPTER 7

CONCLUSIONS AND RECOMMENDATIONS

7.1 RECOMMENDATIONS FOR IMPROVING THE DELIVERY OF COMMUNITY AND HOME BASED CARE

The C&HBC support should continue despite the reduction in numbers of those bedridden with AIDS in homes in order to embrace other chronic illnesses and support those who are terminally ill. Efforts and resources invested in C&HBC programmes by implementing partners have demonstrated some positive benefits for service users and their families. Government should ensure that this support is included in the fiscal health budget and the efforts of other stakeholders should be encouraged.

The MoHCW, as the custodian of health services and policy, ought to take action on the social determinates of health which significantly affects the delivery of C&HBC programmes in Zimbabwe. This can be done by initially raising awareness among policy makers, stakeholders and health professionals on the effect and urgent need to address the issue in all health programmes. Awareness should start during pre-service training of health professionals at training schools. Stakeholders, along with MoHCW, can develop strategies that are compatible with their capacity and resources in anticipation of further partnerships and collaboration. Since programme sustainability without extensive external support is critical, “government should assume a greater role” (Moetlo, Pengpid & Peltzer 2011:142) in the provision of technical and financial support to ensure that the C&HBC programme meets its targets and goals.

Care givers are more knowledgeable in addressing the needs of PLH and those with AIDS than those with other chronic non-communicable diseases even though the C&HBC guidelines stipulate that home based care should include all chronic illnesses. In this regard, care givers are justified in suggesting that their medical supplies for C&HBC should include inhalers, for use in emergencies for asthmatic clients, before referral for professional care. Likewise, community health workers could be trained to provide simple physiotherapy and monitoring of body temperature and blood pressure using simple and available technologies.

Flexibility is required in C&HBC programmes if they are to meet the needs of service users and the community at large. It would be ideal to personalise or tailor care and support to meet service users' needs and goals following an assessment of those needs. However, limitation of resources experienced in Zimbabwe, like in many other poor nations, could cause further strain on already-stretched resources. A less costly option would be to tailor intervention to suit populations within local environmental and social contexts. Furthermore, a strategy such as aligning service users with similar needs and goals per intervention would ensure cost effectiveness in service provision and yield improved results in targeted areas.

Care and support initiatives for chronically ill people should be guided by and directly linked with the development and poverty alleviation strategies of the country to ensure equity and requisite sensitivity to the needs of people with chronic illnesses. C&HBC programmes should be linked to those that ensure livelihoods for families, increase food security and nutrition. Panagides et al (2007:26) suggest an integrated approach to alleviating food and nutrition challenges and that "the approaches should be reframed within a comprehensive approach to tackling the wider structural and systemic deficiencies that fuel susceptibility and vulnerability."

It is essential for service providers to share relevant and streamlined information about patients between organisations that provide integrated services such as C&HBC. The information shared should be restricted to what is essential for an intervention. The application of Information Communication Technologies (ICTs) to health care (Electronic Health or e-health), is alleged to have resulted in significant improvement in communication within the public health system, where it has been applied (Piette, Lun, Moura, Fraser, Mechael, Powell & Khoja 2012:366; Glasgow et al 2008:181). The use of e-health enables information to be accessed from anywhere in the health system. Evaluation of some of the systems has established that it is possible to facilitate communication between care providers, even in remote locations (Suter, Oelke, Adai & Armitage 2009:19). Electronic Health including telemedicine can be applied successfully within C&HBC (including palliative care). The system can be used for a range of functions such as registration of patients, scheduling coordination to sharing patient outcomes. (Simbini, Makowa & Sidatt 2012). Some e-health tools include the use of mobile phones and the internet. Given the rapid developments in technology worldwide

and in Zimbabwe, care givers and chronically ill patients could also be involved in use of the technology through the use of mobile phones. However, the use of information technologies in chronic illnesses is viewed to have many challenges resulting from the complexities of managing conditions which may present with many symptoms needing several treatment protocols. (Glasgow et al 2008:184). Lack of a robust system may be a barrier for success. Therefore, high investment in developing information systems is required, coupled with intensive training for personnel.

Jarvis-Selinger and Bates (2010:9-15) have explored the application of tele-health in home based care for chronic diseases in Canada. They suggest that development and usage of the service should be based on three themes which are: **The patient** – to include self managed care, technology uptake and behaviour change; **The service provider** – ensuring integrated care for facilitation of shared care between a range of service providers; and **policy** – understanding the implications of telehealth services on health care policy and the impact of these services on health human resources and its policy. The scholars conclude that “although patient attitudes and satisfaction are discussed (in tele-health impact studies) more so than effects on clinical outcomes, data quality, clinical effectiveness or economic viability, clinical outcomes have since emerged as an important area of focus in the home based telehealth literature. More has to be done when studying the impact of e-health on patients’ outcomes and quality of life.

The need for pain management was echoed throughout the study from all groups of participants. Pain, especially in HIV-related conditions which range from neuropathy/painful legs to cancers, is usually overlooked. Regular visits to service users by health professionals are essential in home based care, for the purposes of providing palliative care. Chronically ill people require palliative care and such care requires a team of health experts to provide accurate assessment of pain and pain management. Palliative care therefore needs to be integrated within home based care and comprehensive palliative care training provided to all health workers at all levels. An action research in Malaysia (Devi, Tang & Corbex 2008:2063) proved that palliative care can be offered successfully in rural remote areas through home based care with effective organisation and empowerment of nurses and families who are the key drivers of such care.

There are serious inequality and equity issues affecting the most vulnerable members of society when it comes to access to services. A Zimbabwe government-sponsored health insurance scheme for the chronically ill who are unable to afford health services, should be tested and implemented. Financing of the health insurance scheme could be supported from several sources operated on the same principle as the Zimbabwe government administered AIDS Levy.¹ This could constitute a framework for mobilising resources for the scheme. Such a scheme not only serves to meet the health needs and goals of the chronically ill, but also provide a vehicle for the efficient financing and efficient delivery of health services. This efficiency will in turn contribute to the achievement of millennium development goals as implemented at national level. Lessons and best practice could be learnt from other countries that are implementing related schemes. (La Forgia & Nagpal 2012:105).

7.2 CONTRIBUTION OF THE STUDY

This study offers an opportunity for modelling of future C&HBC interventions. This is based on the data analysis and findings, which demonstrate the importance of thorough assessment of priority needs, mapping of community and individual context before programme planning and implementation for better allocation of resources. The unmet needs identified in this study can guide the design of future home based care interventions. Ultimately, this study serves the interests of the C&HBC service users across Zimbabwe. It is possible that if the care of chronically ill people is purpose-designed, this could result in the achievement of goals when specific and varied needs in C&HBC are addressed.

C&HBC programmes can influence policy making in terms of the beneficial effects of integrating medical and social aspects of health in long-term care. The findings of this study can therefore be used to influence the development of interrelated social and health policies as a result of the interlinkage based on social determinants of health. These policy adjustments and reforms can be initiated without waiting for prolonged and bureaucratic processes of change if there is appropriate visioning and will power.

¹ 'AIDS Levy' is a 3% tax on income to increase domestic resources for the national HIV programme. This innovative approach for Zimbabweans to maintain and own their national AIDS responses has enabled Zimbabwe to diversify its domestic funding for its AIDS response, raising an estimated US\$ 26 million in 2011. In 2012, the levy is expected to raise US\$ 30 million.

7.2.1 Future research

Three studies are recommended as a result of observations from this study. The studies should explore and provide greater understanding of areas that are essential for community based health service delivery. The first study proposed should explore the “perceived needs and expectations of chronically ill children within the community health delivery system” in order that the views regarding children’s needs are expressed through evidence-based scientific studies.

Another study should also explore the foundation and role of health education in C&HBC. Health education is the foundation of health promotion and more so in C&HBC, which has complex dimensions of care and support requiring education that goes beyond medical thinking, to include the social determinants of health.

Thirdly, evidence is required on the influence of social determinants of health and inequities in health services in Zimbabwe, in order to find a basis for advocating for interventions for prevention and mitigation of chronic diseases, which are on the increase.

7.3 LIMITATIONS OF THE STUDY

Some of the study participants were in a better state of health and required less care from their primary care givers and community care givers. This infrequent contact with the primary care givers and obsolete experience of the care process was likely to result in recall bias. Service users’ needs have been shifting from acute/sombre to general needs. The likelihood of recall bias due to relapse between the care received during acute illness and the interview (when clients were less distressed), may have increased.

Another challenge that was experienced was that of fewer numbers of primary care givers recruited for interviews, in comparison with service users. It was not always possible to interview service users and their care givers as pairs. Care givers of ambulant service users (who were in the majority) were often away in search of livelihoods or pursuing other business of their own. The role of primary care givers had evidently reduced as service users’ health improved. Some service users were cared for by their own children, many of whom could not be interviewed because they are minors.

Regardless of the constraints above, the research team did all they could to ensure that the study was conducted in a professional manner. Interviews conducted focused on key issues with thorough triangulation of information in order to ensure validity of the study. The interview responses are of value in that they were obtained from 'key informants' perspective i.e. the health professionals; programme implementers, policy makers, community workers and community leaders.

7.4 CONCLUDING REMARKS

Despite the few shortcomings of the study mentioned, the researcher is confident that the study will contribute to an improvement in C&HBC services, through insights and knowledge gained from service users' and key informants' perspectives on priority needs of service users on C&HBC. Useful insight was also gained on how service users view the strategies used to mitigate the needs of chronically ill people. Since the study was confined to a small sample within small study locations, the findings are not generalisable to all areas of Zimbabwe and to all social strata.

It is clear from this study that no single sector can achieve the service users' and programme goals of quality health on its own. These goals may only be realised when other stakeholders and relevant sectors contribute to the C&HBC programme, which requires diverse resources. Imogene King's conceptual model and theory also emphasise the importance of multi-sectoral and multidisciplinary collaboration, effective communication, interaction and transaction, for effective service delivery and service users' care.

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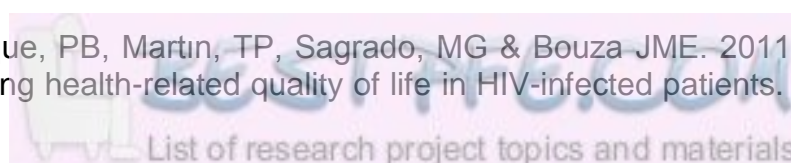
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Annexure 1: Service User Information and Consent Form – English

Information Sheet and Consent Form

My name is carrying out a study for a Doctor of Literature and Philosophy degree In the Department of Health Studies, Faculty of Human Science at the University of South Africa. You are invited to participate in the research study on an evaluation of the needs of service users of Community and Home Based Care (C&HBC). The study has been approved by The University of South Africa Research Ethics Committee as well as the Medical Research Council of Zimbabwe.

However, before you take part, it is important that you understand what it will involve so that you can decide whether you want to take part or not.

Introduction:

The study will try to understand how goals and expectations of C&HBC service users are similar to those of the national health system and those implementing the programme. As part of this study, we would like interview people who are involved in the C&HBC as service users, family, care givers and those with other roles in the programme. The questions we are asking respondents are about the services offered to them as well as their needs and expectations.

The Purpose of the Study:

The study will examine current practice capacity and expectations of community and home based care services. The research will seek opinions and experiences as well as identify barriers and facilitators for the best performance of services.

Risks and Benefits:

We are aware that discussions regarding various aspects of your health and can be time consuming and cause anxiety. You may choose not to participate in this study; it will not affect you in any way.

This is a research project and the findings may be used to design appropriate policies and plan for better home based care health services in the future. As a participant, you may benefit by gaining a better understanding of the home based care services available in your area.

Time Involvement:

If you agree to participate, it will take about 30 minutes to an hour to complete the interview.

Confidentiality:

All the information you provide will be kept in strict confidence. Any information presented will be grouped with that of other participants so that no one will know what you will have said and no names will be written on the structures questionnaires with personal information.

Your individual privacy will be maintained in all published and written data resulting from the study.

Payments: You will not receive payment for your participation.

Your Rights: If you have read and understood this form and have decided to participate in this project, please understand your participation is voluntary and you have the right to withdraw your consent or discontinue participation at any time without penalty. You have the right to refuse to answer particular questions.

Contact Information:

If you have any further questions during the study period and in the future, please do not hesitate to contact the researcher using the following details.

Mrs. Priscilla Mataure, No. 7 Coronation Avenue. Greendale, Harare. Telephone: 498449 / 0772 365 234.

If you have any questions, concerns or complaints about this research study, or feel you have been hurt as a result of this study, you should contact the **Medical Research Council of Zimbabwe**, Josia Tongogara/Mazoe Street. PO Box 573 Causeway, Harare. Telephone: 791792/ 791193/792747

In addition if you are not satisfied with how this study is being conducted, or if you have any concerns, complaints, or general questions about the research or your rights as a participant, please contact the **Research and Ethics Committee at the University of South Africa. Head of Department of Health Sciences. Telephone: +27124296303.**

Informed Consent

I have read (or have had read to me) the contents of this form and have been encouraged to ask questions. I understand about the nature, conduct, benefits and risks of the above study.

My participation is voluntary. My decision as to whether or not to participate in this study will not jeopardize the standard of care I receive in future. I am free to decline to be in this study, or to withdraw from it at any point without giving a reason. I have received answers to my questions. I agree to participate in this study

Participant's name _____ (please print)

Participant's signature _____ Date: _____

I hereby certify that the service user has agreed to participate in this study and herewith confirm that the above service user has been informed fully

Researcher's name _____ (please print)

Researcher's signature _____ Date _____

A copy of this information sheet and consent form is for you to keep.

Annexure 2: Service User Information and Consent Form – Vernacular

Information Sheet and Consent Form

Kwaziwai ini ndinonzi mai..... uye ndiri mudzidzi wegwaro repamusoro rakanangana nezveutano. Ndirikutsigirwa muzvidzidzo zvangu ne University ye South Africa (UNISA) pamwe neboka rinoringira neongororo dzedzidzo dzeutano reMedical Research Council of Zimbabwe.

Musoro Wenyaya

Ndirikukukokai kuti muve umwe wevanhu vachabatsira kudaira mibvunzo nekupa humbowo muongororo yemabasa etsigiro inopiwa nemhuri uyezve nevagari venharaunda dzinogara vanhu vanezvirewe zvisingarapike. Muchirungu mabasa etsigiro dzevarwere ava inodaidzwa kuti Community and Home Based Care (C&HBC). Musati mabvuma kupinda muhurongwa hweongororo iyi ndirikuda kukupai tsanangudzo izere pamusoro pezvinangwa zvedzidzo iyi.

Chinangwa Cheongororo Iyi

Chimwe chezvinangwa zvedzidzo iyi kuedza kunzwisisa kuti pane kuenzana here mutarisiro dzevarwere nehurongwa webato rehurumende rehutano rinotsigira varwere vanorapiwa mumisha. Muongororo yandikuita ndichange ndichibvunza nekutsvaga pfungwa dzenyu maererano nebasa rinobatwa nemhuri uyezve vanambuya hutano vanobata sei basa ravo mudzimba kana munharaunda dzavanoshandira.

Zvinetswa Uye Mibairo Yebasa Iri

Tinoziva kuti hurukuro dzakanangana nezvehutano hwenyu nemagariro emhuri yenyu dzinotora nguva yakareba. Pamusoro pazvo mimwe mibvunzo iri maererano nemaitiro enyu nezveutano hwenyu inogona kukonzera kusagadzikana. Mukasarudza kusava nhengo yeongororo hazvina zvazvishakanganisa kwamuri.

Ongororo yose iyi nezvichawanikwa mairi zvinogona kushandiswa kugadzira mitemo nehurongwa hunobatsira kuwanisa ruyamuro rwuri nani mune zveutano mune ramangwana. Senhengo yeongororo munogona kuwana ruzivo rwuri nani rwekwekurapirwa pamba rubatsiro rurimo munzvimbo dziri munharaunda yenyu.

Nguva Ichatorwa

Kana mabvuma kupinda muongororo, iyi, zvinogona kutora nguva iripakati pe30minutes ne hour imwe kuti ndibvunze mibvunzo uye ndikurukure nemi.

Kodzero Dzevachapinda Muchirongwa

Kana maverenga uye mazvipira kuti mupinde muongororo iyi, ndapota, nzwisaisai kuti muri kuita izvi pasina kumanikidzwa uye kuti mune kodzero yekubuda kana kuregedza chero pane ipi zvayo nguva pasina muripo kana kurasikirwa kwamunoita nekodzero dzenyu. Mune mvumo yekuramba kupindura chero upi mubvunzo wamunenge musinga fare nawo. Chimiro chenyu uye danho renyu semunhu akazvimiririra pachake (privacy) zvichachengetedzwa nenzira kwadzo muzvinyorwa kana mushambadziro yezvichabuda mutsvakiridzo ino.

Mubhadaro Kana Mubairo

Ndapota nzwisaisai kuti hapana mubhadaro wamuchawana nekupinda muongororo iyi.

Kwekutiwana kana pane mibvunzo, zvichemo, zvinyunyuto kana zvimwe zviziviso

Kana muine mibvunzo, zvichemo kana zvinyunyuto maererano neongororo ino, kubvira maitirwo ayo, njodzi kwamuri kana zvamungawana kana dzimwe nzira dzekurapwa bvunzai vakuru vechirongwa vanonzi: **Priscilla Mataure** – Foni yekumba inoti **498449**, foni mbozha inoti **0772365234**; email mmataure@zol.co.zw

Munofanirwa kuvatsvaga paneipi nguva mukanzwa kuti makuvadzwa nokuda kwekuva nhengo yeongororo iyi.

Nhengo dzakazvimirira: Kana musina kugutsikana nemaitirwo eongororo, kana kuva nezvichemo, zvinyunyuto kana mibvunzo nezveongororo kana kodzero dzenyu senhengo yeongororo, tapota zivisai ve**Medical Research Council of Zimbabwe**, Josia **Tongogara/Mazoe Street. PO Box 573 Causeway, Harare. Foni: 791792/ 791193/792747**

Ndapota kanazve paine imwe nzwisiso yemungada kuanayo pamusoro pekufambiswa kweongororo iyi kana nemabatiro ebasa racho zivisaiwo **veResearch and Ethics Committee** yeku **University of South Africa** muchishandisa kero inoti: **Head of Department of Health Science** panhare inoti: **+27124296303**.

Gwaro Rekutenda Kuvamuongororo

Ini ndaverenga/ndaverengerwa ndikanzwisisa zvakanorwa mugwaro iri uye ndinozvipira kudaira mibvunzo yabvunzwa. Ndinoziva kuti ndinogona kusadaira chero upi mubvunzo wandinenge ndisina kufara nawo zvisingazondi kanganisire kodzero dzangu. Ndabvuma kupinda muongororo uye ndapiwa tsanangudzo izere pamibvunzo yandavunza pamusoro pechidzidzo ichi.

Zita reari kudaira mibvunzo.....(nyora zvinooneka)

Saina zita rako pano.....Date:.....

Ndinopupura kuti murwere abvuma kuti ave mungororo iyi uyezve ndinonzwisisa kuti iye murwere aziviswa zvizere nezveongororo iyi.

Zita remuongorori.....(nyora zvinooneka)

Saina zita rako pano.....Date:.....

Annexure 3: Clearance from the University of South Africa



UNIVERSITY OF SOUTH AFRICA

Health Studies Research & Ethics Committee

(HSREC)

Faculty of Human Sciences

CLEARANCE CERTIFICATE

Date of meeting: 31 July 2011

Project No: 48-194-794

Project Title: An investigation into home and community based health care programmes in Zimbabwe: an analysis of the congruency of service users' needs and the programme goals

Researcher: Priscilla Mataure

Supervisor/Promoter: Prof Gloria Thupayagale-Tshweneagae

Joint Supervisor/Joint Promoter: N/A

Department: Health Studies

Degree: DLITT ET PHIL (Health Studies)

DECISION OF COMMITTEE

Approved



Conditionally Approved




Prof TR Mavundla

RESEARCH COORDINATOR


Prof MC Bezuidenhout

ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES

PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES

Annexure 4: Approval from the Research Council of Zimbabwe

Telephone: (263) - 4 - 791792/791193
Telefax: (263) - 4 - 790715
E-mail: mrcz@mrczimshared.co.zw
Website: <http://www.mrcz.org.zw>



Medical Research Council of Zimbabwe
Josiah Tongogara / Mazoe Street
P. O. Box CY 573
Causeway
Harare

APPROVAL LETTER

Ref: MRCZ/B/264

20 October 2011

Priscilla Mataure
University of South Africa (UNISA)
Department of Health Sciences

RE: An Investigation into Home and Community Based Health Programmes in Zimbabwe: An Analysis of the Congruency of Service Users's Needs and the Programme Goals.

Thank you for the above titled proposal that you submitted to the Medical Research Council of Zimbabwe (MRCZ) for review. Please be advised that the Medical Research Council of Zimbabwe has **reviewed** and **approved** your application to conduct the above titled study. This is based on the following documents that were submitted to the MRCZ for review:

a) Study protocol

- **APPROVAL NUMBER** : MRCZ/B/264
- This number should be used on all correspondence, consent forms and documents as appropriate.
- (i) **EFFECTIVE APPROVAL DATE** : 20 October 2011
- (ii) **EXPIRATION DATE** : 19 October 2012
- (iii) **TYPE OF MEETING** : Expedited Review

After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ Offices should be submitted one month before the expiration date for continuing review.

- **SERIOUS ADVERSE EVENT REPORTING:** All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ Offices.
- **MODIFICATIONS:** Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Offices is required before implementing any changes in the Protocol (including changes in the consent documents).
- **TERMINATION OF STUDY:** On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Offices.
- **QUESTIONS:** Please contact the MRCZ on Telephone No. (04) 791792, 791193 or by e-mail on mrcz@mrczimshared.co.zw.

Other

- Please be reminded to send in copies of your research results for our records as well as for Health Research Database.
- You're also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours Faithfully

MRCZ SECRETARIAT
FOR CHAIRPERSON
MEDICAL RESEARCH COUNCIL OF ZIMBABWE



PROMOTING THE ETHICAL CONDUCT OF HEALTH RESEARCH

Registered with the USA Office for Human Research Protections (OHRP) as an International IRB (Number IRB00002409 IORG0001913)



ZIMBABWE AIDS NETWORK

31 August 2011

The Director,
Red Cross Society,
Fact Rusape
Mashambanzou

Dear Partners

RE: Request for authorization and facilitation of Community and Home Based Care

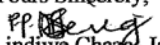
We refer to the above matter. We have been approached by Ms Priscilla Mataure, who is public health expert, with a request for authorization to conduct public health research in the area of community and home based care. She has a nursing background, with a Masters Degree in Health Systems management. She has extensive experience with SAFAIDS, UZ Department of Community Medicine, and Zimbabwe Red Cross (1991-1993), and the Ministry of Health and Child Welfare.

As ZAN, we recommend and support this initiative as it will deliver evidence on the appropriateness and responsiveness or otherwise of this community based intervention and we request that you kindly assist her in this regard. As ZAN we have requested that the research documents whether published or unpublished should acknowledge all the organisations that will have participated in the research. The main research document and other technical guidelines that may be generated from the process will also similarly be shared and acknowledge all key stakeholders who will have participated in this process.

She will need your written approval to support the application for clearance from the Medical Research Council of Zimbabwe (MRCZ). Find attached hereto the official application letter to ZAN, Research Proposal and Certificate of Approval for conduct of the research from UNISA Department of Health Sciences. Your response is requested on or before **Wednesday 7 September 2011**, the field work is expected to last 8 months from the time of MRCZ approval.

Please contact the undersigned should you require any further clarification. Thank you for your continued support in the national response to HIV and AIDS.

Regards,

Yours Sincerely,

Lindiwe Chaza Jangira
National Director

Annexure 6:

Letter of Approval from Mashambanzou Trust



Mashambanzou
40 Sandown Road, Waterfalls,
Harare, Zimbabwe
P O Box W 190, Waterfalls, Harare, Zimbabwe
Tel/Fax: +263 (0)4 610937
Tel: +263 (0)4 610079
WO 9/90

Email : mashambanzoumail@mashambanzou.co.zw
www.mashambanzou.co.zw

20th September 2011

Ms Priscilla Mataure
7 Coronation Avenue,
Greendale, Harare

Dear Ms P Mataure,

Re: Authorisation and Facilitation to Conduct a Community and Home Based Care Study Through Our Organisational Structures.

In response to your request to work through Mashambanzou Care Trust to carry out a research study entitled, *"An Investigation into Home and Community Based Health Care Programmes in Zimbabwe: An Analysis of the Congruency of Service Users' Needs and the Programme Goals"*, I am pleased to inform you that your request has been granted.

Kindly provide us with a detailed work plan on the activities that you will be carrying out on a weekly basis and the people you would like us to facilitate your meetings with so that we may assist you accordingly.

We wish you the best as you apply for clearance with the Medical Research Council of Zimbabwe and with your overall study.

Yours Faithfully

Sister Ivy Mudangandi

Coordinator

Annexure 7: Letter of Approval from Family AIDS Caring Trust-Rusape

**FAMILY AIDS CARING TRUST
RUSAPE PVO 17/2005**



Tel: +263-25 3491/ 3364

Fax: +263-25 3491

Email:

Cell: 011 786 625

275 Tait Avenue

P.O. Box 495,

Rusape,

Zimbabwe

16 September 2011

Dear Mrs Priscilla Mataure

**RE: Application to Conduct a Research in HBC in FACT Rusape Programme
In Marondera**

I write to acknowledge receipt of your application for permission to conduct a research on our C & HBC Projects in Marondera with support from Zimbabwe AIDS Network. The Management of FACT Rusape approved your request. The Coordinator, Mr G. R. G. Kaserera will assist and share with you the ethical issues that the organisation expects to be upheld. FACT Rusape will be grateful if you could share with us the research findings on completion of the study.

Yours Faithfully

Portipher Guta
EXECUTIVE DIRECTOR
FACT Rusape
Box 495
Rusape
Tel: 025-3364
Cell: 0912 806 974
Email: portipher@factrusape.org or portipher@factrusape.org

"By love serve one another" Galatians 5:13

Annexure 8: Letter of Support from Harare City Health Department



CITY OF HARARE

Director of Health Services
DR STANLEY MUNGOMA
MD (Cuba) MPM (Zim)

All correspondence to be addressed to the
DIRECTOR OF HEALTH SERVICES
1/30

DIRECTOR OF HEALTH SERVICES
Rowan Martin Building,
Civic Centre,
Parnell/Kether Avenue,
off Rotten Row,
Harare, Zimbabwe.
P. O. Box 896
Telephone: 753316
753330-1-2
Fax: (263-4) 752093

24 MAY 2012

Priscilla Mataure (Mrs) MSc.
No. 7 Coronation Avenue
Greendale
HARARE

Dear Madam

RE: **PERMISSION TO CARRY OUT A STUDY ON HOME
BASED ACTIVITIES IN THE CITY OF HARARE**

Your request is acknowledged.

Permission is granted for you to interview health personnel in management positions and responsible for Community and Home Based activities at Head Office, Kuwadzana, Mbare, Mabvuku and Dzivarasekwa.

Kindly liaise with the Sisters In Charge of the requested clinics for further assistance.

Yours faithfully

DIRECTOR OF HEALTH SERVICES

PNM/rw

cc. Sisters In Charge - Kuwadzana Polyclinic
- Mbare Polyclinic
- Mabvuku Polyclinic

**Annexure 9: Letter of Support from Provincial Medical Directorate
(Ministry of Health and Child Welfare)**



Telephone: 24207/8, 24571

Telegraphic Address:
"PROVMED, MARONDERA"
Fax: 23967 / 21994

ZIMBABWE

Reference:

MINISTRY OF HEALTH AND
CHILD WELFARE
PROVINCIAL MEDICAL DIRECTOR
(MASHONALAND EAST)
P.O.BOX 10
MARONDERA
ZIMBABWE

1 March 2012

The District Medical Officer
P.O. Box 20
Marondera

Att: Dear Sir


Re: INTRODUCTION OF MRS PRISCILLA MATAURE (UNISA)

Reference is hereby made to the above.

This minute serves to introduce Mrs Priscilla Mataure who is carrying out a research into Home and Community Based Health programmes in Zimbabwe and specifically in Marondera District. She is doing this in conjunction with FACT as approved by the Medical Research Council of Zimbabwe.

May you therefore give the team the necessary support they may require.

Thank you.


Dr B. Madzima
Acting PMD- Mash East

Cc File



Annexure 10: Quantitative Data Collection Instrument for Service Users
Service Users' Structured Questionnaire

Questionnaire Number: _____

Interviewer's name: _____

Date: _____

District and Ward/Area: _____

Demographic Information

1. Service User Gender: 1. Male 2. Female

2. Service User Age: 1. 18 - 25 yrs, 2. 26 - 33yrs 3. 34 - 41yrs 4. 42 - 49yrs
5. 50 - 57yrs 6. 57 + yrs

3. Religion: 1. Christian 2. Islam 3. Traditional 4. None

4. Occupational Status: 1. Casual Labour 2. Farming 3. Formal Employment
4. Informal Employment 5. Petty Trading 6. (Other Specify)-----

4b) If not employed, what is your source of income?

1. Remittances 2. Donations 3. Begging 4. Cash Transfers
5. Other (Specify) _____

5. Marital Status: 1. Single/never married 2. Married
3. Divorced/Separated. 4. Widowed 5. Cohabiting

6. Level of Education: 1. Non- formal 2. Primary 2. Secondary
4. Tertiary

7. How long on current HBC: ----- months
-----years

General Questions

1. What condition are you suffering from? (Please circle as many as may apply)

1. Cancer
2. HIV or AIDS
3. Tuberculosis
4. Diabetes
5. Mental Illness
6. Other (specify) _____

2. When did you first know that you have this illness? (Please circle one)

1. Less than a year ago
2. One year ago
3. About two years ago
4. More than 2 years ago
5. A long time back
6. I really cannot remember

3. What is your greatest fear/concern right now?

4. What are the main problems you are facing as a result of your illness? (circle all that apply)

1. Physical
2. Social
3. Economical
4. Spiritual
5. Emotional
6. Other: Specify _____

b) Explain:

5. Roughly what is your monthly income? (Please circle one)

1. None 2. \$1 - 20 3. \$ 21- 50, 4. \$51-100, 5. \$101-200, 6. \$201-500,
7. \$501-1000, 8. Above \$1000

6. Who takes care of you at home? (Specify your main caregiver) (Please circle one)

1. My spouse
2. My mother
3. My sister/brother
4. My Child
4. My grandchild
- 5 My grandparent
6. My Neighbour
7. A community carer giver from the village
8. Other (specify) _____

7. List the care providers who visit you regularly? (circle all that apply)

1. Doctor
2. Nurse
3. Social Worker
4. Community Care Giver
5. Other (Specify)

8. Did you choose the care provider/s who care for you? 1. Yes 2. No

8b) Who chose those/that care provider/s to care for you?

9. Do you know what services are offered by the C&HBC Programme? 1. Yes 2. No

9b) If yes, what are they?

10. What role does **your family play** in the care that you receive? (to help you maintain your independence and achieve the best possible quality of life)

11. What role do **health care providers** play in the care that you receive? (to help you maintain your independence and achieve the best possible quality of life)

12. A lot of times people have commented that people with long term illnesses benefit much if they are being cared for at home. How is this experience with you?

Health Needs and Service User Satisfaction

1. What would you say are your needs (in order to meet your health expectations) as a person with a chronic illness? (circle as many as may apply)

I need:

1. my symptoms (pain, nausea, insomnia, etc.) to be better controlled
2. help with eating, dressing, and going to the bathroom
3. information about my condition
4. better dialogue with care provider/s
5. respect for my privacy
6. to speak with a spiritual advisor
7. to feel more useful within my family
8. food
9. economic assistance
10. other (specify_____)

2. Are these needs met? 1. Yes 2. No 3. Sometimes 4. Some of them

2b) If not why do you think those needs were not met?

3. In your opinion, how can those needs be met?

4. How have you and your family tried to meet these needs?

5. What information do you receive from your care providers concerning your illness/condition?

The next questions are about how you feel about the medical care you receive.

The section highlights what people say about medical care, keeping in mind the home based care you are receiving now. If you have not received care recently, think about what you would expect if you needed care today. We are interested in your feelings, good or bad about the care you have received.

6. How strongly do you agree, disagree with each of the following statements. Circle one number on each line.

Statement	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
1. Care providers are good at explaining about my illness, care and treatment.	1	2	3	4	5
2. The medical care I have been receiving is just about perfect	1	2	3	4	5
3. I have easy access to health care providers	1	2	3	4	5
4. My health care providers treat me very friendly and in a courteous manner	1	2	3	4	5
5. I have some doubts about the ability of care givers who care for me.	1	2	3	4	5
6. Care providers visit me many times a month	1	2	3	4	5
7. I am dissatisfied with something about the care I receive	1	2	3	4	5
8. My care providers sometimes ignore what I tell them	1	2	3	4	5
9. My care providers are very competent and well trained	1	2	3	4	5
10. When I am receiving care, they should pay more attention to my independence.	1	2	3	4	5
11. During my care, I am always allowed to say everything that I think is important	1	2	3	4	5
12. The care providers who visit me should give me more respect	1	2	3	4	5
13. Those who provide medical care sometimes hurry too much when they treat/care for me.	1	2	3	4	5
14. Care providers involve me in making decisions about my own health care and needs.	1	2	3	4	5

7. How has the visiting home care team helped you in general? (Please circle all that apply)

- 1 By providing drugs
- 2 Providing counselling
- 3 They provide me with foodstuffs
- 4 Financially
- 5 Health education
- 6 Other (specify) _____

8. What other help would you like the visiting home care team to give you? (Please circle as many)

- 1 Drugs/medication
- 2 Legal Support
- 3 Spiritual support
- 4 Foodstuffs
- 5 Family support (counselling.)
- 6 Financial support
- 7 All the above
- 8 Other (specify)

Quality of Life

1. *Quality of life means different things to different people.* Would you like to tell me what the concept "quality of life" mean to you?
2. Has your quality of life changed since you were enrolled in C&HBC? 1. Yes 2. No
- 2b) How?
- 2c) What exactly do you think made the difference?
2. In your opinion what would you say your health is like: **(Please circle one response)**
1. Excellent 2. Very good, 3. Good, 4. Fair 5. Poor
3. What activities are you able to do in order to care for yourself to live normally?
 1. Wash and clean myself up
 2. Walk around the house
 3. Cook
 4. Do physical exercise
 5. Do house chores
 6. Work in the garden
 7. Other (specify) _____
4. What activities are you **NOT** able to do in order to care for yourself to live a normal life?
 1. Wash and clean myself up
 2. Walk around the house
 3. Cook
 4. Do physical exercise
 5. Do house chores
 6. Work in the garden
 7. Other (specify)
5. In the last **3 months**, how often have you felt the following?

*For each symptom below, choose your response from the **answer key** and place the corresponding number of your answer in the space beside each symptom. For example, if your answer for **headache** is **seldom or never**, place the number 1 on the line beside **headache**.*

- a. ____ Headache
- b. ____ Stomach-ache
- c. ____ Backache
- d. ____ Feeling low (depressed)
- e. ____ A bad mood (irritable)
- f. ____ Feeling nervous (uneasy)
- g. ____ Difficulties getting to sleep
- h. ____ Feeling dizzy
- i. ____ Fatigue
- j. ____ General body pain
- k. ____ Other (specify)

ANSWER KEY

- 1 = seldom or never
- 2 = about once every month
- 3 = about once every week
- 4 = more than once a week
- 5 = most days

6. What would you like to do in the next six months to improve or maintain your health?
 1. Go for medical check up
 2. Adhere to medicines
 3. Exercise
 4. Eat a healthy Diet
 5. Other (specify) _____
7. What would stop you from making this change or enhance the change?
 - a) **Stop:**
 - b) **Enhance:**
8. In your own opinion, how can your family help improve your quality of life?
 - 1 Provide for my drugs/medication
 - 2 Facilitate Legal Support
 - 3 Facilitate Spiritual support
 - 4 Provide Foodstuffs
 - 5 Provide Health education
 - 6 Provide counselling.
 - 7 Provide Financial support
 - 8 All the above
 - 9 Other (specify)_____
11. How can care providers improve your quality of life?
 - 1 Provide Drugs/medication
 - 2 Facilitate Legal Support
 - 3 Facilitate Spiritual support
 - 4 Provide Foodstuffs
 - 5 Provide Health Education
 - 6 Provide counselling.
 - 7 Provide Financial support
 - 8 All the above
 - 9 Other (specify)_____
12. Is there something that C&HBC should have done differently for you?
13. Do you have any suggestions or comments you would like to share with me about your needs and expectations of community and home based care?

Thank you for taking the time to respond to this questionnaire.

Annexure 11: Quantitative Data Collection Instrument for Family Care Givers

Interview Guide for Family Caregivers

Questionnaire No. _____ Interviewer's name: _____

Date: _____

District and Ward/Area: _____

Demographic Information

1. Respondent's Gender: 1. Male 2. Female
2. Age: 1. 18 - 25 yrs, 2. 26 - 33yrs 3. 34 - 41yrs 4. 42 - 49yrs
5. 50 - 57yrs 6. 57 + yrs
3. Religion: 1. Christian 2. Islam 3. Traditional 4. None
4. Occupational Status: 1. Casual Labour 2. Farming 3. Formal Employment
4. Informal Employment 5. Petty Trading 6. (Other Specify) _____
- 4b). If not employed, what is your source of income?
1. Remittances 2. Donations 3. Begging 4. Cash Transfers
5. Other (Specify)- _____
5. Marital Status: 1. Single/never married 2. Married 3. Divorced/
Separated. 4. Widowed 5. Cohabiting
6. Level of Education: 1. Non- formal 2. Primary 2. Secondary
4. Tertiary
7. Relationship to service user: _____
8. How old is your service user? _____

Service User Needs

1. How did you come to be looking after this service user?

1. Volunteered
2. Assigned
3. Obligated
4. Compassion
5. Other (specify)

2. Were you given any kind of training to do what you are doing? 1. Yes 2. No

2b) If so, what kind of training?. 1. Formal 2. Informal

2c) For how long?

1. Less than 1week
2. One week
3. Two Weeks
4. Three weeks
5. Four Weeks
6. Other (specify)_____

3. Do you feel confident to care for the service user? 1. Yes 2. No

b) Explain:

4. Does the service user tell you about his/her needs? 1. Yes 2. No

4b) If so, what are the service user's needs? (*Complete table below*)

List of Needs	Were They Met? Yes/No	By Who?

4c) Who above did you find to be the most helpful in assisting with meeting the needs?

5. Who do you discuss the service users' needs with in order to come to a health care decision and plan? (Please circle all that apply)

1. Family Member
2. Friend/neighbour
3. Health Provider
4. Service user
5. No one
6. Other (specify) _____

6. Indicate how frequent the home visits from health workers are?

	3 times a week	Once a week	Once a month	Other (specify)
Professional health workers				
Community Health workers				

7. What problems do families generally come across when they are faced with a chronic illness?

8. Does the sick person appreciate what you do for him/her? 1. Yes 2. No 3. Sometimes

b) Explain.

9. What exactly do you do in caring for this service user? *(Please circle all that apply. Do not give options but probe)*

1. Assess service users' needs
2. provide physical assistance (bathing, walking etc)
3. provide counselling
4. Administration of medication
5. Provide information and education
6. Carry out household Tasks
7. Provide spiritual support
8. Other (specify) -----

10. What major problems are you encountering as you look after this service user?

1. Inadequate medication
2. Food Insecurity
3. Inadequate C&HBC kits
4. Lack of Transport
5. Other (Specify)_____

11. If the service user's condition changes or the service user develops a problem where do you go for help?

1. Community Health Worker
2. Clinic/Hospital
3. Community leader
4. Traditional Healer
5. Other (Specify)_____

12. What are your own most pressing needs (as a care giver) right now?
- 12b) How do you think they can be met?
13. Given a/another chance to be trained in looking after this service user, what things would you like to learn?
14. What assistance, if offered, would make it easier for you to look after this service user?
15. What symptoms does your service user commonly experience?
1. Headache
 2. Stomach-ache
 3. Backache
 4. Feeling low (depressed)
 5. A bad mood (irritable)
 6. Feeling nervous (uneasy)
 7. Difficulties getting to sleep
 8. Feeling dizzy
 9. Fatigue
 10. General body pain
 11. Other (specify)
16. In some situations, people with chronic illnesses experience poor physical, mental or psychological health which would keep them from doing usual activities such as self care, work or recreation. How has this been with your service user?
17. Indicate how often family members participate in the care of the service user
- | Never | Rarely | Often | Always |
|-------|--------|-------|--------|
| | | | |
18. How often do you involve the service user in decision making process about their health and care?
- | Never | Rarely | Often | Always |
|-------|--------|-------|--------|
| | | | |
19. How often do health workers involve you in the decision making process about the service user's health and care?
- | Never | Rarely | Often | Always |
|-------|--------|-------|--------|
| | | | |
20. From your own experience, what are the challenges of meeting yours and your service user's needs in C&HBC?
21. Do you have any suggestions or comments you would like to share with me concerning the care needs, and your expectations of the C&HBC programme?

Thank you for taking the time to respond to these questions.

Annexure 12: Interview Guide for Key Informants

Interview Guide for Community Leaders and Secondary Care Givers

Interviewer's name: _____

Date: _____

District and Ward/Area: _____

Respondent's Gender: _____

Position/Title _____

- 1 What are the main health problems in your village/community?
- 2 Which diseases do you think are incurable/chronic?
- 3 How does the community here cope with these diseases?
- 4 What do you think are the most common (a) needs and (b) problems of the terminally ill?
- 5 How best do you think these various needs can be met?
- 6 What needs of chronically ill service users are being met or not met. For those not met, find out....
 - a) Reasons why?
 - b) Whether or not there are appropriate skills to meet needs and goals of both service users and health system.
 - c) Are the needs and expectations beyond what is mandated or any other reason?
- 7 What local resources are available to help the chronically ill and their families?
- 8 What problems do families have when faced with a chronic illness at home? How can the community here support these people and their families?
- 9 What sort of health services would you want people with chronic illnesses in your community to have?
- 10 What strategy is there for community participation? Are local beneficiaries consulted and involved as appropriate?
- 11 How best do you think the government can help the chronically ill and their families?
- 12 Any other comments/issues you would like to share about the needs, care and expectations of the community and home based care programme.

Thank you for taking the time to respond to these questions.

Annexure 13: Interview Guide for Health Facility Personnel

Interviewer's Name: _____

District and Ward/Area: _____

Name of Health Facility _____

Category of Health Facility e.g. General Hospital, Health Centre: _____

Ownership of Health Facility e.g. Government, Mission: _____

Respondent's Gender: _____

Position/Title _____

1. What is the role of the hospital/clinic in the home based care services?
2. Where do chronically ill service users' prefer to be looked after during illness?
3. What are these service users' greatest needs during their time of sickness?
4. Which of the needs are met? Why these and how are they met? If there are needs that are not easily met, why is that so? Who meet these needs?
5. What problems does the health facility face as it renders the home care services?
6. What more would you want to do for chronically ill service users? (Things that are not normally provided)
7. Is the programme succeeding in meeting service users' goals and objectives (probe-how do you know whether it's succeeding or not?)
8. What lessons have you learnt in your C&HBC programme which contributes to the body of knowledge in Zimbabwe? (negative and positive) How have these been used to strengthen programme?
9. From your own experience, what are the challenges of C&HBC in Zimbabwe?
10. Is there anything that can be done differently? What and Why?
11. Do you have any suggestions or comments you would like to share with me about the care needs and expectations of service users on home based care?

Thank you for taking the time to respond to these questions

Annexure 14: Interview Guide for Programme Implementers/Managers

District and Ward/Area: _____

Name of Organisation _____

Respondent's Gender: _____

Position/Title _____

1. What are the goals and objectives of your home based care programme?
How are these goals and objectives being achieved? (probe on the service package) Is the programme succeeding in meeting its HBC objectives (probe- how do you know whether it's succeeding or not?)
2. What criteria do you use to identify those needing home care and the services they require?
3. Please comment on the human resources level of proficiency and adequacy for implementing this programme?
4. What sort of in-service training (if any) do the staff receive to help them do their work?
5. What problems does the staff encounter in delivering these services?
6. What do you consider to be the needs of chronically ill service user?
7. What, in your view, are the major problems that the chronically ill service user faces?
8. What needs of chronically ill service users are being met or not met. For those not met, find out....
 - a) Reasons why?
 - b) Whether or not there are appropriate skills to meet needs and goals of both service users and health system.
 - c) Are the needs and expectations beyond what is mandated or any other reason?
9. What plans do you have to improve/develop these services in future?
10. What key indicators are you monitoring and evaluating this programme?
11. How do you measure quality of life as a result of HBC interventions? (What else do you measure to show programme outcomes)
12. How does your programme link up with other similar (or not similar) services in the community?
13. What is the role of the community in the home care service delivery? (Probe for participation and decision making)
14. What lessons have you learnt in your C&HBC programme which contributes to the body of knowledge? (negative and positive) How have these been used to strengthen programme?
15. What are the strengths and challenges of the C&HBC programme?
16. The goal of C&HBC programme in Zimbabwe is to make appropriate quality health services available to all chronically ill people. What is your experience in relation to this goal?
17. Please comment on the role of the government in the delivery of home care services?
18. What recommendations would you make concerning the future delivery of home care services with regard to service integration, community participation, and incorporation of service users' needs and expectations?
19. Do you have any other suggestions or comments you would like to share with me about the care needs and expectations of service users on home based care?

Annexure 15: Interview Guide for Ministry of Health Personnel

Interviewer's name: _____

Date: _____

Name of MOHCW Department: _____

Respondent's Gender: _____

Position/Title _____

1. What is the role of the Ministry in the home based care services in Zimbabwe?
2. What is the goal of the C&HBC programme in Zimbabwe?
3. What is your experience in relation to this goal? Is the programme consistent with national goals and expectations?
4. Is the programme succeeding in meeting its C& HBC objectives (probe- how do you know whether it's succeeding or not?)
5. What are the key outcomes of measure for the success of the C&HBC? How are they measured?
6. What chronically ill service users' needs are being met or not met. For those not met, find out....
 - a) Reasons why?
 - b) Whether or not there are appropriate skills to meet needs and goals of both service users and health system.
 - c) Are the needs and expectations beyond what is mandated or any other reason?
7. What problems/constraints does the Ministry face as it controls the implementation of home based care services to meet its goal?
8. Is there a clear strategy for community participation and decision making in the design, implementation and evaluation of C&HBC services? How are local beneficiaries of C&HBC consulted and involved as appropriate?
9. What are the strengths and challenges of C&HBC in Zimbabwe?
10. What lessons have you learnt in C&HBC programmes which contribute to the body of knowledge? (negative and positive) How have these been used to strengthen the programme nationwide?
11. What plans does the Ministry have to manage and sustain the home care services in future?
12. What recommendations would you make concerning the future delivery of home care services with regard to service integration, community participation, and incorporation of service users' needs and expectations?
13. What other improvements/changes would you like to see?
14. Do you have any other suggestions or comments you would like to share with me about the care needs and expectations of service users on home based care?

Thank you for taking the time to respond to these questions

Annexure 16: Focus Group Discussion Guide for Service Users

1. In your opinion, what are the characteristics of a healthy community? (*Warm up question*)
2. What are the characteristics of a healthy individual with quality of life (*Let the group define quality of life and agree on definition*).
3. What are the main health problems in your village/community? (*Allow free listing and then prioritize the three most important ones*)
4. Which diseases are incurable/chronic and common in your community? (*Allow free listing and then prioritize to four most common ones in the area*)
5. Who (what kind of person) is the most affected by those incurable diseases? (Ascertain general beliefs and attitudes to chronic illnesses i.e. young, old, male or female, children, behavioural and traditional factors.)
6. How does the community here cope with these diseases? (*Probe for treatment/coping strategies – medical care/HBC, traditional healing, spiritual, etc.*)

IF C&HBC IS NOT MENTIONED ASK WHETHER THE SERVICE IS THERE AND WHAT THEY THINK ABOUT IT (The services provided. If C&HBC is mentioned also ask about the service provided as well)

7. What are the most common needs among people with incurable/chronic diseases? (re-identify the diseases first and get the needs for each disease)
8. How have they been met? If not met....how best do you think these various needs can be met?
9. What other needs do people with these illnesses have?
10. How can **the community** help people who are chronically ill and their families?
11. What other of health services would you like to see provided for people with chronic illnesses in your area?
If those services are provided how can they be maintained/sustained? *Check and probe for community participation, decision making and involvement? What strategy exists for community participation? Are local beneficiaries consulted and involved as appropriate? (If cost sharing is mentioned what would be the minimum charge per person?)*
12. How best do you think **the Ministry of Health** can help the chronically ill and their families?
13. Any other comment/s you would like to share with us about the care needs and expectations of service users on home based care?

Thank you very much.

Annexure 17: Focus Group Discussions and Key Informants Interviewed

Key Informants

Name	Area/Organisation	Position	Discussion Focus Area
Ms Mary Mafrutu	Mashambanzou, Harare	C&HBC Team -Nurse Responsible for home visits	
Mr Robert Mawonera	Mashambanzou, Harare	Nurse Manager, Palliative Home Care	
2 Community Home Based Care Coordinators	Mabvuku High Density Area, Harare	Mashambanzou trained Community Care Givers	Female Respondents
Mr Charles Kautare	Kuwadzana Ward 37 Harare	National AIDS Council Ward Focal Person (Advocacy Chairperson for PLHA)	
3 Community Home Based Care Coordinators	Kuwadzana Ward 37 Harare	Community Care Givers	Female Respondents
Mrs A Somanje Mrs J Mutizirirwa	Marondera/Rusike High Density Area	Child Protection Society Community Workers (Work in liaison with C&HBC Care givers)	
Ms Georgina Mahachi	Idawekwako Old Aged Home-Marondera	Care giver (Formally Trained in C&HBC)	
4 Community Home Based Care Coordinators	Wenimbe East-Marondera Rural	Community Care Givers	2 males and 2 females interviewed
Ms Lorraine Chimombe	FACT Rusape	Programme Officer	
Mr Josiah Nyahoda	Ward 6 Marondera District	Councillor (Community Leader)	
Ms Rumbidzai White	Garikayi- Marondera	Care Giver (Worked for several organisations as a community worker)	
2 Community Home Based Care Coordinators	Green Well Farm. Marondera District	Community Care givers	Female Respondents
Mr Soul Ndowora	Ruwari Resettlement-rural Ward 23	Community Care Giver	
Ms M Marwa	Kushinga Phikelela Rural Health Centre	Nurse Manager	
1 Female Respondent	Mbare High Density Area	Community Care Giver	
Mr Raymond Yekeye	National AIDS Council	Director of Programmes/Operations	
Ms Caroline Sirewu	National AIDS Council	National Home Based Care and Support Coordinator	
Dr B Madzima	Mashonaland East	Medical Officer/Acting	Policy issues around

	Province and Marondera District (Ministry of Health)	Provincial Medical Director	home based care and future direction of the programme
Ms Mercy Fadzi	Marondera District	District Nursing Officer	
Mr Sebastian Manjengwa	Marondera District National AIDS Council	District AIDS Action Committee	
Ms M Makunike	Kuwadzana Municipality Clinic, Harare	Nurse Manager Family Health Services	
Ms Priscilla Mkahanana	Edith Opperman Municipality Clinic, Harare	Nurse Manager Community Health Services	
Ms Mercy T. Mutsago	Matapi Municipality Clinic. Harare	Acting Nurse Manager Family Health Services	
Ms Evelyn S. Mukarakate	Rujeko Clinic Municipality Harare	Acting Nurse Manager Family Health Services	
Ms Kumbi Musarurwa	Mabvuku/Tafara Municipality Clinic, Harare	Nurse Manager Community Health Services	Clinics role in C&HBC Service Users' Needs. Challenges of health service delivery for service users with chronic illnesses

Focus Group Discussions

Area/Venue	No. Male	No. Female	Type of Group/Comments
Tafara High Density Area (Urban)	3	9	Service Users and Caregivers
Tafara High Density Area (Urban)	0	6	Community Care Givers
Dzivarasekwa H/Density Area (Urban)	6	10	Service Users and Care Givers
Dzivarasekwa H/Density Area (Urban)	2	8	Community Care Givers
Mabvuku High Density Area (Urban)	4	4	Service Users and Care Givers
Kuwadzana High Density Area (Urban)	1	5	Service Users and Care Givers
Mbare High Density Area (Urban)	3	8	Service Users and Care Givers
Marondera/Rusike High Density Area (Urban)	0	10	Service Users and Care Givers
Wenimbe Ward 6 (Rural)	1	7	Service Users and Care Givers
Wenimbe Ward 6 (Rural)	4	4	Community Care Givers
Garikayi -Marondera (Peri-urban)	0	8	Service Users and Care Givers
Kushinga Phikelela (Rural and from 3 wards)	4	3	Community Care Givers

Annexure 18: Certificate of Editing

THIS IS TO CERTIFY THE EDIT OF THE DOCTORAL THESIS ENTITLED

**An Investigation into Home and Community-Based Healthcare
Programmes in Zimbabwe: An Analysis of the Congruency of Service-Users
Needs and the Programme Goals**

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UNIVERSITY: UNISA

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