A CRITICAL ASSESSMENT OF THE QUALITY OF COMMUNITY HOME-BASED CARE

By

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In accordance with Rule G4.6.3, I hereby declare that the above-mentioned thesis is my own work and that it has not previously been submitted for assessment to another University or for another qualification.

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Dedication

To Pam, Peter and Carolyn Morton

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Ad Majorem Dei Gloriam

ABSTRACT

Volunteer home-based caregivers are critical role players in South Africa’s health care system and in the South African government’s strategy to fight HIV and AIDS. In order to achieve the aims that the government seeks to attain, it is important that the care and treatment provided to patients receiving community home-based care (CHBC) be of a high quality. While the need for quality care is supported by government and civil society, research indicates that it is not clear whether quality care is indeed being provided and therefore there is a need for research into the quality of CHBC.

The research aimed to undertake a critical assessment of CHBC programmes to determine the quality of care provided by volunteer caregivers using social capital theory as a theoretical framework. The study examined the quality of CHBC by analysing the context of CHBC, by investigating the support that volunteer caregivers and their clients receive and by discussing the support that volunteer caregivers and their clients still need. The study used one-on-one in-depth interviews and focus groups to obtain relevant data. The participants included volunteer caregivers, clients and supervisors who took part in the one-on-one interviews. The focus groups consisted of key informants and supervisors respectively. The quantitative data consisted of descriptive statistics which helped describe the participants. The qualitative data was coded and themes and sub-themes were developed. The data was also analysed by an independent coder.

The results showed that poverty, and the related problems of poor living conditions and a lack of food security affects the quality CHBC. In addition, unemployment and the problem of stipends also affect quality CHBC. Certain socio-economic factors were also found to lead people to choose to become volunteer caregivers and unemployment was found to be an important driving force behind the choice to undertake volunteer caregiving. Furthermore, the volunteer caregivers in the sample received organisational support from their supervisors and their fellow caregivers or peers. They also received social support from their families and their communities. Regarding the clients of the volunteer caregivers, it was found that they received a number of types of support including psycho-social counselling, spiritual counselling and care of a holistic nature. In addition, the study found that there is a need for standardised quality training of volunteer caregivers, which will equip them with multiple skills. It was also found that volunteer caregivers require mentoring and quality supervision in order to be able to provide quality CHBC to their clients.

Government has the ability to put the necessary systems and structures in place, such as a scope of practice for volunteers, standardised training and monitoring and evaluation, to enable CHBC and its relevant role players to operate at optimum levels. It also has the authority to make the changes and to enforce rules. Furthermore, it has the ability to unite CHBC organisations and can create the necessary conditions that can lead to increased social capital. Furthermore, the study recommends that two additional dimensions of quality care be added to existing dimensions of quality in health care. The first is the holistic approach to caregiving and the second is social support systems, namely supervisor/mentor and peer support and family and community support. This second dimension is also closely linked to social capital and the networks that make up CHBC.

KEYWORDS:

Community home-based care
HIV and AIDS
Quality care
Social capital
Volunteer caregivers

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ABBREVIATIONS

AIDS: Acquired immune deficiency syndrome

ARV: Antiretroviral

ATICC: AIDS Training, Information and Counselling Centre

CBO: Community-based organisation

CHBC: Community home-based care

DoH: Department of Health

DOTS: Directly observed treatment short course

DSD: Department of Social Development

FAMSA: Family and Marriage Society of South Africa

FBO: Faith-based organisation

FCG: Family caregiver

FG: Focus group

HBC: home-based care

HCT: HIV counselling and testing

HIV/AIDS: Human immunodeficiency virus/acquired immune deficiency syndrome

HIV: Human immunodeficiency virus

HSRC: Human Sciences Research Council

ICHC: Integrated community home-based care

IEC: Independent Electoral Committee

LDC: Least developed country

NGO: Non-governmental organisation

NMBM: Nelson Mandela Bay Municipality

NPO: Non-profit organisation

NSP: National Strategic Plan

OVC: Orphans and vulnerable children

PLHA(s): Person(s) living with HIV or AIDS

PLHIV: People living with HIV or AIDS

PLWHA: People living with HIV and AIDS

PWA: People living with AIDS

RTI: Research, Technology and Innovation

SACLA: South African Christian Leadership Assembly

STD: Sexually transmitted disease

STI: Sexual transmitted infection

TAC: Treatment Action Campaign

TB: Tuberculosis

UK: United Kingdom

UN: United Nations

UNAIDS: Joint United Nations Programme on HIV/AIDS

USA: United States of America

USAID: United States Agency for International Development

VCG: Volunteer caregiver

VCT: Voluntary counselling and testing

WHO: World Health Organisation

CHAPTER 1
INTRODUCTION

1.1 Introduction

Chapter 1 introduces the concepts of community home-based care (CHBC) and volunteer home-based caregivers. First, the study is contextualised with an overview of the literature regarding CHBC and related issues. Second, the rationale of the study is presented with evidence supporting the need for a study of this nature. Third, a problem statement is presented discussing the phenomenon of CHBC and the factors affecting it. Fourth, the research questions and the aims of the study are presented. Fifth, there is an explanation of the purpose of the study. Sixth, the significance of the study is presented. Seventh, the demarcation of the study is discussed, explaining the geographic and social parameters. Finally, the structure of the thesis is laid out for the reader.

1.2 Contextualising the study

This study focuses on volunteer home-based caregivers because current literature illustrates that volunteer caregivers in southern Africa play a vital role in caring for clients with a variety of diseases, including the Human Immunodeficiency Virus (HIV) and the Acquired Immune Deficiency Syndrome (AIDS), tuberculosis (TB), malaria, cancer and a range of other chronic and terminal illnesses (Kikule, 2003; Lindsey, Hirschfeld, Tlou, & Ncube, 2003; McCreary, Nkosazana, Popovich, Dresden, & Mndebele, 2004). According to the *National Guideline on Home-Based Care / Community-Based Care*, developed by the Department of Health (DoH), volunteer caregivers in CHBC programmes are called to care for the following groups (DoH, 2001, Rationale for HC section, para. 3):

- healthy people
- at risk or frail older persons
- at risk people with moderate to severe functional disabilities
- people recovering from illness, in need of assistance e.g. post deliveries or after specific treatment.
- terminally ill persons

- persons living with HIV/AIDS or any other debilitating disease and/or conditions e.g. mental illness, substance abusers
- any other disadvantaged group/person in need of such care e.g. people in crisis.

Therefore, volunteer caregivers care for a wide range of people with a wide range of ailments and diseases. However, much of the current study will be in the context of the HIV and AIDS epidemic, as it was the rapid spread of this disease that led to the formation of CHBC programmes in the first place (Tshabalala, 2008, p. 8).

There is a need for volunteer home-based caregivers to assist those with HIV and AIDS because of the many health-related challenges faced in South Africa. For instance, poverty, crime and violence, government indifference, gender inequality and scarce medical and social resources make the daily living conditions of people affected by HIV and AIDS in South Africa a continuous struggle (Demmer, 2006). As a result, fighting the disease is a complicated battle, especially due to the high numbers of infected and affected people. Add to this the challenge of providing effective care and support to large numbers of people living with other chronic diseases such as TB, and the AIDS crisis appears overwhelming (Ahn, Grimwood, Schwarzwald, & Herman, 2003). With governments unable to cope alone, it is evident that there is a great need for voluntary support and therefore research in the area of HIV and AIDS care, simply based on the large numbers of people affected by the disease.

Indeed, the magnitude of the problem is evident in UNAIDS statistics that show that in 2009 South Africa was the country with the highest HIV epidemic in the world with an estimated HIV population of between 5.4 and 5.8 million people (UNAIDS, 2010). This is approximately 17.8 per cent of the total population of South Africa (DoH, 2010). In 2009, the estimated HIV prevalence of pregnant women attending antenatal clinics in the Eastern Cape Province was 28.1 per cent, and the percentage in the Nelson Mandela Bay Municipality (NMBM), where this study takes place, was 30.7 per cent (DoH, 2010). This is a very high percentage for the NMBM, and is in fact higher than the national average of 29.4 per cent (DoH, 2010). The challenge is how to care for these growing numbers of sick people and hence delay their imminent death.

Because of the large number of people with HIV and AIDS, there is tremendous pressure on the public health care system to accommodate the effects of the AIDS epidemic. A national survey of the impact of HIV and AIDS on the health sector revealed that 46.2 per cent of patients served in the medical and paediatric wards of public hospitals in South Africa were HIV-positive (Shisana & Simbayi, 2002). This has led to overcrowding in hospitals and in some areas, hospitals have up to 120 per cent of their beds occupied (Bateman, 2001), which suggests that patients may be sharing beds, or sleeping on the floor, which is unacceptable from a health care perspective. In another study by Bateman (2010), it was noted in 2009 at Groote Schuur Hospital in Cape Town, admissions increased by 40 per cent, but at the same time there was a reduction in available hospital beds. As a result, care for people with AIDS and other chronic illnesses is hampered by shortages of hospital beds, inadequate numbers of public sector health professionals, and a lack of resources for treatment and drugs (DoH, 2001). Often patients with curable illnesses are side-lined in the hospitals due to the high number of patients with HIV and AIDS (Bateman, 2001). Hence, Campbell and Foulis (2004) argue that the burden of care that would normally have been the responsibility of public institutions has fallen onto individuals, households and communities.

When the HIV epidemic first began in Africa and particularly in South Africa, the main objective of activists was to prevent the further spread of the virus. However, it was only when the HIV epidemic progressed into an AIDS epidemic that policy-makers began to take a more serious look at care and treatment (Ogden, Esim, & Grown, 2004). Towards the late 1990s, policy-makers became concerned with the logistics of a rapidly growing AIDS population and a public health care sector which clearly was not coping with the large number of people seeking care. They sought alternatives, and the shifting of clinical care from public health care institutions to communities became a possible solution to the problem. This brought about a focus on CHBC and the role of the volunteer caregiver.

Despite health care access being upheld in the South African Constitution as a human right, hospital care is inaccessible to many South Africans (Harris, Goudge, Atagubab, McIntyre, Nxumalo, Jikwana & Chersich, 2011). Therefore, it is not surprising that Nsutebu, Walley, Mataka and Simon (2001) argue that CHBC could be a useful alternative with major health and social benefits for persons living with HIV or AIDS (PLHAs), and their families, including being a platform from which to strengthen HIV prevention. In many African countries, CHBC programmes were implemented by non-profit organisations (NPOs) in order to provide services unavailable through health care institutions (Rosenberg, Mabude, Hartwig, Rooholamini, Orraca-Tetteh, & Merson, 2005). In South Africa, despite considerable challenges, many NPOs with the help of thousands of volunteer caregivers have attempted to grapple with the HIV and AIDS care and support needs of their communities (Russel & Schneider, 2000).

1.3 Rationale

The following is the rationale on why research on CHBC and volunteer home-based caregivers is of great importance at this time. Furthermore, the reasons for research on quality CHBC are also discussed.

First, the need for research on informal or lay volunteer caregivers is essential as formal care is currently not coping with the large numbers of people with chronic illnesses, particularly HIV and AIDS. This is supported by Akintola (2010), who states that “informal caregivers are a critical source of support for the majority of people living with HIV/AIDS worldwide…. This is particularly true in the southern Africa region, which has countries with some of the highest HIV/AIDS prevalence rates in the world” (p. 1).

In addition, quality CHBC is also a priority of the South African government, as demonstrated by its *National Strategic Plan (NSP) for HIV and AIDS, STIs* [sexually transmitted infections] *and TB, 2012-2016* (DoH, 2011). According to this plan, four pillars have been developed indicating its focus areas over the next five years. One of the pillars focuses on health and wellness (DoH, 2011, p. 9) and reveals the central role of quality:

- Health and wellness – the primary objective being to ensure access to *quality treatment* [own emphasis], care and support services for those with HIV and/or TB and to develop programmes to focus on wellness.

Thus, there is a need to investigate if this key objective, namely quality treatment, is being achieved in CHBC. The NSP document demonstrates the concern on the part of government regarding a need to improve the "quality of services" (DoH, 2011, p. 49) in the context of healthcare.

The strategic plan supports the important link between CHBC and its role players in providing quality care and treatment to people with chronic illnesses. This is evident from the following:

> Community-based services have a critical role to play in expanding the quality and reach of health and wellness services – proactively taking programmes and services to people has been demonstrated to increase service uptake. The massive increase in HIV prevention, care and treatment services in the last five years, mainly through international funding to community-based organisations [CBOs] and NGOs [non-governmental organisations], has ensured major scale up. (DoH, 2011, p. 48)

The DoH (2007b) compiled a document entitled: "A Policy on Quality in Health Care for South Africa." The document discusses CHBC in a number of places, highlighting the importance of community involvement with regard to quality health care. Hence, this aspect of the document further supports the role of CHBC as an important part of the government's vision for quality healthcare in South Africa.

An earlier DoH document, the DoH *National Guideline on Home-Based Care / Community-Based Care* (2001) also emphasizes the importance of quality, as it aims to "promote and ensure quality of care, safety, commitment, cooperation and collaboration" (p. 4). Furthermore, the DoH states that it wishes to create a health system whereby "all formal and informal healthcare stakeholders work together to provide effective, efficient and high-quality care to PLHIV [people living with HIV or AIDS] and other patients" (Boros, 2010, p. 316). Hence, the challenge is to determine if CHBC programmes actually provide "high-quality care" to their clients as this care can only be effective if it is of sufficiently high quality (Nsutebu et al., 2001).

However, despite this emphasis on quality, it is questionable whether the care is always of sufficiently high standard. For instance, Campbell and Foulis (2004) state: “Research by social scientists lags disappointingly behind developments in [CHBC] policy and practice. To date little systematic research has been conducted into the evolution, nature and *effectiveness* [own emphasis] of indigenous grassroots responses to the challenges of HIV prevention and AIDS care” (p. 5). Hence, they argue that there is a scarcity of knowledge regarding the effectiveness, and hence quality, of CHBC, which means that much remains to be learned about CHBC volunteer caregivers and their ability to care effectively for their patients. Another aspect of CHBC is palliative care and Webster, Lacey and Quine (2007, p. 30) note that “in the majority of developing countries, little is known about the quality of care that people receive at the end of life.” Therefore, there is a need for further research on quality care in the context of palliative CHBC.

Thus, volunteer home-based caregivers are critical role players in South Africa’s healthcare system and in government’s strategy to combat HIV and AIDS. In order to achieve the government’s strategy, it is important that the care and treatment provided to patients is of a high quality. While the need for quality care is supported by government and civil society, the literature indicates that it is unclear whether quality care is indeed being provided; thus further research into the quality of CHBC provided by volunteer caregivers is essential.

1.4 Problem statement

A major challenge for South Africa is how to care for the many people living with AIDS, TB and other chronic and terminal illnesses in South Africa. South Africa also has high levels of poverty, which is exacerbated by the AIDS and TB epidemics. Twenty-eight per cent of the world’s HIV and TB co-infections are found in South Africa (USAID, 2011). Poverty and poor levels of education combine to impact negatively on other social issues such as healthcare, gender inequalities and stigma. In response to these poverty-related issues communities rallied forming CHBC organisations in an attempt to combat all the challenges faced by them. Hence, the context in which CHBC is being provided is both multifaceted and complex, especially from a socio-economic point of view.

Besides the clients, the volunteer caregivers are the main role players in CHBC programmes. They are expected to provide quality care to their clients. However, there are many factors that can influence whether or not the care they provide is of a good quality. Some variables are more difficult to quantify such as the motivation behind their decision to volunteer.

Factors that affect the volunteers' ability to provide quality care include the support that they receive from their CHBC organisations. Such support can vary from material support to emotional or psychological support. Alternately, a lack of organisational support could have a negative effect on the quality of care that volunteers are able to provide to their clients. Hence, the challenge is to determine what factors influence the quality of care provided by volunteer caregivers to their clients.

1.4.1 Research questions

The researcher seeks to provide answers to the following broad research question regarding volunteer caregivers who are affiliated to CHBC programmes in the NMBM:

- **What is quality CHBC?**

Three main research questions seek to answer this broad question. Underneath each main research question are a series of more specific sub-questions.

- **What are the socio-economic factors influencing CHBC and their impact on quality CHBC?**
  - What are the socio-economic aspects underlying the context of CHBC?
  - What socio-economic factors motivate people to become volunteer caregivers?

- **What support do the clients of volunteer caregivers currently receive and how does this impact on quality CHBC?**
  - What kinds of support do clients receive from their volunteer caregivers?

- **What support do volunteer caregivers currently receive inside and outside of CHBC organisations, and how does it impact on quality CHBC?**
    - What kinds of organisational support do volunteer caregivers receive?
    - What kinds of social support do volunteer caregivers receive?

- **What macro and micro socio-economic challenges need to be overcome to enable volunteer caregivers to provide quality CHBC?**
    - What kinds of operational support do volunteer caregivers still need?
    - What government support do volunteer caregivers still need?

1.5 Aims and objectives

The purpose of the study can be summed up in the following thesis statement: To undertake a critical assessment of CHBC programmes to determine the quality of care provided by volunteer home-based caregivers using social capital theory as a theoretical framework. Therefore, the focus of this study is CHBC service provision by volunteer caregivers affiliated to NPOs running CHBC programmes.

The quality of CHBC will be shown by:

- Analysing the context of CHBC
- Investigating the support that volunteer caregivers and their clients receive
- Discussing the support that volunteer caregivers and their clients still need

1.6 Significance of the study

Firstly, this study is significant as it will examine the care provided by volunteer caregivers from a number of CHBC organisations in the NMBM. This has never been done before and should serve as a useful baseline concerning CHBC organisations for future research in this field.

Secondly, it will assess the care provided by these volunteer caregivers using a variety of research methods that involves all the actors who work with or support these volunteer caregivers. The benefit of including all those involved with the caregivers is that it will contribute to a greater understanding of CHBC and volunteer caregivers in particular.

Thirdly, as the rationale indicates that there is a need for further research in the area of CHBC, the study will be of value as it will add to current literature concerning CHBC, especially literature that deals with quality CHBC.

Fourthly, the study will add to the literature regarding the support that volunteer caregivers and their clients receive. It will also contribute to an understanding of the support that volunteer caregivers and their clients still need.

Finally, the study will contribute to a greater understanding of the structural needs required for CHBC to operate effectively and so that quality care can be provided. The structural needs will be determined by examining the various challenges that are faced by the role players involved in CHBC.

1.7 Definition of key concepts

1.7.1 **Client:** The client, also sometimes referred to as a patient, is the person being cared for in his or her home by a volunteer home-based caregiver.

1.7.2 **Community Home-Based Care (CHBC):** Community Home Based Care provides "comprehensive care services at home and at community levels in order to meet the **physical, psychological, social and spiritual needs** of terminally ill clients including PLWHAs [People Living With HIV and AIDS] and their families" (National AIDS Coordinating Agency, 2008, para. 1).

1.7.3 **HIV and AIDS:** HIV is the acronym for Human Immunodeficiency Virus and AIDS is the acronym for Acquired Immune Deficiency Syndrome. Van Dyk (2008, p. 4) explains the acronym as follows: The illness is *acquired* as it is not a genetic condition. Its cause is the human immunodeficiency virus, which originates externally. *Immunity* refers to the ability of the human body to protect itself from infection and disease. *Deficiency* refers to the inability of the immune system to protect itself from infections. The medical term *syndrome* refers to "a collection of specific signs and symptoms that occur together and that are characteristic of a particular condition" (Van Dyk, 2008, p. 4).

1.7.4 **Manager:** In the context of this study, a manager is a person running a CHBC programme. In many cases, this person will also be a supervisor and even a volunteer.

1.7.5 **Non-Profit Organisation (NPO):** This term includes the following organisations: community-based organisations (CBOs), faith-based organisations (FBOs) and non-governmental organisations (NGOs).

1.7.6 **Supervisor:** The function of the supervisor is to coordinate groups of volunteer home-based caregivers. Cameron (2003) states that the role of the supervisor is to "nurture and mentor the caregivers, and identify and address problem areas" (p. 36).

1.7.7 **Volunteer caregiver:** A volunteer caregiver is a community member who volunteers his or her time to caring for individuals in the community who have chronic or terminal illnesses, such as HIV and AIDS.

1.8 Demarcation of the study

This thesis focuses on CHBC programmes in the NMBM, thus covering the urban areas in Port Elizabeth and Uitenhage. Only programmes run by NPOs were considered for the study. Hence, none of the programmes in this study were government programmes, ensuring that the focus remained on the volunteers who have become so essential to combating the AIDS epidemic in South Africa. Indeed, there may have been government involvement in the programmes, as far as funding or training was concerned, but the programmes that were chosen were independent and autonomous.

All the managers, supervisors, volunteer caregivers and clients who took part in the study were from CHBC programmes in the NMBM. The key informants and the focus group participants have all been involved in CHBC or related work in the NMBM.

1.9 Structure of the thesis

Following on from Chapter 1 is Chapter 2, the literature related to CHBC. The literature examines the broader context of CHBC as well as a more detailed analysis of the concept together with certain key documents that are guiding the implementation of the concept. Chapter 3 presents the theoretical framework of the study. This chapter describes how social capital theory will be used as the lens through which the study will be viewed. Chapter 4 presents the methodology of the study, including a discussion of the sampling procedure, the research methods and the data collection process. The results and discussion are presented in Chapter 5 which covers all the data acquired from the interviews, focus groups and the questionnaires. As the findings are presented they are followed-up with a discussion around them. Finally, the conclusion of the study is presented with a summary of the findings and a discussion of the limitations and recommendations of the study.

1.10 Conclusion

This chapter provided an overview of the structure of the thesis. First, the study was contextualised by describing CHBC and volunteer caregivers. Second, the rationale for the study was presented, providing the reasons why a study of this nature is necessary. Third, the problem statement described the need for CHBC and the support that volunteer caregivers require. Thereafter, the research questions were presented, followed by the aims of the study. Next, the purpose of the study was summed up in a thesis statement, after which followed the significance of the study. Key concepts in the study were then defined and the demarcation of the study was described, followed by a presentation of the structure of the thesis.

CHAPTER 2
LITERATURE REVIEW

2.1 Introduction

The chapter introduces community home-based care (CHBC) by defining and describing it. A short history of CHBC follows. Then there is a presentation of the South African Department of Health's (DoH's) *National Guideline on Home-Based Care/Community-Based Care* and then an overview of home-based care (HBC) and CHBC. Following this is a discussion of three of the CHBC models. Next is a discussion of CHBC in relation to AIDS and South Africa, AIDS and gender inequality, AIDS and stigma, and AIDS and poverty. Volunteering and volunteers' willingness to care are then discussed. Then, the main role players in CHBC are presented, namely supervisors, caregivers, and clients followed by a discussion of the various caregiver activities. After which monitoring and evaluation and training are discussed. Following this is a discussion of the benefits and disadvantages of CHBC, and finally, quality care is examined in relation to CHBC.

2.2 Community home-based care

Below are presented a series of definitions and descriptions of CHBC, starting with a World Health Organisation (WHO) definition, in order to explain the function of CHBC. Following this section is a presentation of the history of CHBC, with specific reference to Africa and South Africa.

2.2.1 Defining community home-based care

The WHO definition of CHBC is as follows: "any form of care given to sick people in their homes. Such care includes physical, psychosocial, palliative and spiritual activities" (WHO, 2002, p. 8). Since CHBC consists of these four aspects of care, it means that the caregivers need to be equipped to provide these different types of care for their clients. The WHO definition also makes a distinction between physical and palliative, and psychosocial and spiritual activities, which could in some respects be combined. Furthermore, the WHO emphasises that an important aim of CHBC is "to provide *hope* through *high-quality* and appropriate care that helps family caregivers (FCGs) and sick family members to maintain their independence and achieve the best possible quality of life" (WHO, 2002, p. 8, own emphasis). The WHO definition makes it clear that quality care is an important aspect of CHBC. In other words, CHBC is meant to be of a high standard in the same way that more formal health care is also expected to be of a high standard.

The South African DoH (2001), drawing on the WHO definition of home care, states that:

> Home care is defined as the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person's maximum level of comfort, function and health including care towards a dignified death. Home care services can be classified into preventive, promotive, therapeutic, rehabilitative, long-term maintenance and palliative care categories. (p. 1)

Furthermore, it emphasises the community aspect of CHBC stating that it is "the care that the consumer can access nearest to home, which encourages participation by people, responds to the needs of people, encourages traditional community life and creates responsibilities" (DoH, 2001, p. 1). Besides the emphasis on community, this definition is people-centred and can be considered to be in accord with the people-centred model of health care as opposed to the more traditional models of health care which are often "overly biomedical oriented, disease focused, technology driven and doctor dominated" (WHO, 2007, p. 6). In addition, this definition indicates that the DoH wishes to decentralise health care (Marais, 2005).

The WHO definition for long-term home care insists that informal caregivers should have access to services that will assist them in providing the necessary care to their clients (WHO, 2000).

> People who require *home-based long-term care* may also need other services, such as acute physical or mental health care and rehabilitation, together with financial, social, and legal support. Informal caregivers should therefore have access to supportive services, including

> information on and assistance in securing help, training, and respite. (Definition section, para. 1, 2, 4, own emphasis)

The WHO emphasises the importance that volunteer caregivers receive every kind of support in their work of caring for their clients. Furthermore, the implication is that such support is to come from outside the community, because despite the volunteers providing services to their clients, they themselves require support services in order to do this. It appears that one of the main sources of such support would be government agencies. The WHO does not expect volunteer caregivers to operate in isolation, but to be part of the continuum of health care which is linked to more formal structures.

Schneider and Russel (2000) define CHBC as such:

> All AIDS activities that 1) are based outside conventional health facilities (hospitals, clinics, health centres), but which may have linkages with the formal health and welfare sector; and 2) that address any aspect of the ‘continuum of care and support’, from time of infection through to death and impact on survivors. (p. 328)

This broad description indicates that there is a network of actors involved in the process of CHBC and in fact the definition refers to “linkages” between the informal and “the formal and welfare sector”. In the context of social capital this implies linking or vertical ties, which result from “hierarchical or unequal relations due to differences in power or resource bases and status” (Islam, Merlo, Kawachi, Lindström & Gerdtham, 2006, p. 6). In the case of CHBC, volunteer caregivers are able to access knowledge and skills from health care professionals, thus strengthening the social capital in the communities where CHBC is taking place.

Based on these definitions, it is clear that CHBC is not a one-dimensional form of care, but in fact consists of a complex system of role players. None of the above definitions suggest that CHBC should replace traditional institutional care or that it should be equal to such formal care. But perhaps this is one of the weaknesses of the above definitions, namely that it is not indicated explicitly that the concept of CHBC is not meant to be a substitute for institutional care.

2.2.2 History of community home-based care

Home care first emerged in the 1980s, in developed countries such as those in North America and Europe and was a response to the AIDS epidemic (Spier & Edwards, 1990). In the United States of America (USA), the *National Home Care Association* was founded in 1982 to "provide high-quality care to hospice and home patients, and to act as the industry's voice" (Home Care, n.d., p. 840). CHBC programmes were begun in order to help manage rising hospital costs in the USA and due to the difficulties experienced by families and home caregivers in caring for persons living with HIV or AIDS (PLHAs) (Spier & Edwards, 1990). For similar reasons in Africa, CHBC programmes were implemented by non-profit organisations (NPOs) to provide services that were unavailable through care institutions (Rosenberg, Mabude, Hartwig, Rooholamini, Oracca-Tetteh, & Merson, 2005).

2.2.2.1 Africa

Illife (2006) indicates that it is difficult to determine the exact origins of CHBC, but Rosenberg et al. (2005) note that in Africa, CHBC programmes were first formed in the late 1980s in Uganda and Zambia. One of the earliest instances of CHBC was *The AIDS Support Organisation* (TASO), which was started in Uganda in 1987, with 16 volunteers (Akintola, 2004). Another early response to the AIDS epidemic in Africa was the *Salvation Army Hospital* in Chikankata, Zambia, with its CHBC programme for PLHAs, also starting in 1987 (Chela & Siankanga, 1991). These two organisations were used as models by other CHBC organisations in Africa (Abdool Karim, Kalibala, Katabira & Stein, 2002). Illife (2006) identifies another pioneer of CHBC in Zambia as the Catholic Diocese of Ndola, which began its care work in 1991 and by the late 1990s had mobilised 500 volunteer caregivers in 25 townships. The largest CHBC organisation in southern Africa is *Catholic AIDS Action*, which was founded in Namibia in 1998, and in 2002 had 39 staff members and over 1000 volunteers across the country, and was founded on the Ndola model (Illife, 2006).

2.2.2.2 South Africa

Community health care workers, a term that encompasses lay community volunteer workers, have been in South Africa since before the 1980s (Schneider, Hlophe & Van

Rensburg, 2008), for example, they were operating in townships for the *South African Christian Leadership Assembly* (SACLA) Health Project in Cape Town (Mathews, Hewitson & Van der Walt, 1991). One of the earliest home care initiatives was the *South Coast Hospice*, in Port Shepstone, founded in 1983 to care for people with terminal illnesses such as cancer (Lauden, 1999). Another example is described by Stuart (1994) regarding an early CHBC pilot programme in KwaZulu-Natal which covered five health districts in 1991.

CHBC programmes for PLHAs began in earnest in the mid-1990s, when the AIDS epidemic became much more apparent in South Africa (Akintola, 2004). At the time, the South Coast Hospice in Port Shepstone responded to the situation, because having an established rural outreach programme it was suitably equipped to respond to the needs of PLHAs (Lauden, 1999).

In South Africa, according to the DoH (2004, p.9), "the provision of home and [CHBC] programmes … increased from 466 in 2001/2002 to 892 in 2003/2004 with over 50 000 beneficiaries." From these figures it is evident that CHBC is becoming more prevalent in South Africa, although the figures do not indicate the size and the types of programmes in operation. As a result, the South African government had to re-think the issue of CHBC and hence they developed a *National Guideline on Home-Based Care / Community-Based Care* on how to manage CHBC.

2.3 National guideline on home-based care / community-based care

In 2001, the South African government released a *National Guideline on Home-Based Care / Community-Based Care,* as a guide to all the various stakeholders taking part in CHBC. At the beginning of the document, the DoH (2001, p. 2) lists the following reasons why CHBC is necessary in South Africa:

- Shortage of hospital beds.
- Inadequate number of medical, nursing and allied health professionals in the public sector.
- Lack of resources for treatment and drugs.
- Increasing demands of curable conditions on existing institutional care.

- Hospitals, which are crowded and over-stretched, are often unsuitable for managing patients with terminal or long term diseases.
- Cost of institutional care.

It appears that all the points listed above are directly or indirectly due to the fact that the DoH does not have the necessary budget to cope with supporting a struggling health care system. If there was an adequate budget, hospital beds could be bought; medical staff could be paid better wages and discouraged from moving to private institutions or emigrating; resources and medicines would be more easily obtainable; primary health care clinics could be expanded to handle those with curable conditions in the community and new hospitals could be built or old ones expanded. Admittedly there are other mitigating factors that impact on health care delivery. However, it is very clear that CHBC is being encouraged by the government, because it is seen as a way to ease the financial burden of the DoH. To illustrate the size of the budget allocated for the purposes of health in South Africa, the DoH’s budget grew by 16 per cent from R18 billion in 2009/10 to R21,5 billion in 2010/11 (Burger, 2011).

As mentioned in Chapter 1, the DoH foresees CHBC programmes as assisting a wide range of people, not only PLHAs and the terminally ill, but also elderly people, disabled people, disadvantaged people and even healthy people. Hence, there is a strong emphasis on community and inclusivity. There appears, on the part of government, to be a desire to make health care a responsibility of all communities. This is supported by the *National Guideline on Home-Based Care / Community-Based Care* which envisages community caregivers assisting:

- families
- caregivers from the formal system, for example, professionals
- caregivers from the non-formal system, for example, NGOs [non-governmental organisations], CBOs [community-based organisations]
- caregivers from the informal system, for example, community health workers, volunteers, other community caregivers and church groups (DoH, 2001, p. 4).

The desire on the part of government to involve communities in health care has not gone unchallenged with among others, Marais (2005, p. 65) arguing that “the ethic of care as a household and community responsibility – its veritable ‘privatization’, consigning it to the sphere of the home – has coincided with the increasingly implacable subordination of social life to the rules of the market.” Marais’s argument has political and economic ideological overtones, which of course cannot be ignored and which may be valid. However, this study will be adopting the stance that at the moment there appears to be no viable alternative to CHBC for many South Africans.

2.4 Overview of community home-based care

This section provides an overview of CHBC. First, the principles of CHBC are set out. Second, this is followed by a section on the goals and objectives of CHBC. Third, the stakeholders in CHBC are investigated. Fourth, the section ends with a discussion of the three pillars of CHBC.

2.4.1 Principles of home-based care and community home-based

The DoH *National Guideline on Home-Based Care / Community-Based Care* provides a list of principles on which CHBC is to be based (DoH, 2001, pp. 4-5). The following section paraphrases the principles, indicating in italics the word(s) that capture(s) the respective principles: CHBC is expected to be *holistic*, encompassing physical, social, emotional, economic and spiritual factors. It is also meant to be *person-centred* and community-driven, which is unlike the traditional models of health care. CHBC is called to be *comprehensive* whereby all role players in the community and in institutional health care work together (“multi-sectoral”) for the good of the sick person. It is aimed at being *empowering* so as to allow the patient and the FCG “functional independence.” The guideline requires that patients have *access* to support services and that these cover the *total lifespan* of the patient. *Resources* are to be identified which are sustainable and cost effective and the responsibility of the resources is to be shared. *Quality care* and *safety* are to be both ensured and promoted. The principles call for *choice* and control over the extent to which partners will participate in the CHBC process. *Diversity* is to be emphasised together with equal opportunities, rights and independent living. CHBC programmes should be *specific* in what needs to be done and achieved. The focus on the basic and essential components of primary health care leads to an emphasis on *community involvement*.

The above principles are useful for CHBC organisations to guide them in their care of sick people in their homes. However, some of the principles are vague and ambiguous and in some instances it is not clear to whom the principle is referring. For example, the reference to resources is vague because who is to share the responsibility of the resources? How should the responsibilities be shared? Of course these are a set of principles and it is not expected that they be very detailed. However, ambiguity is not helpful either. Ideally, a set of principles should be linked to each CHBC model, which would enable them to provide more specific directions.

2.4.2 Goals and objectives of community home-based care

Here are the goals of CHBC as laid out by the DoH (2001, p. 8):

- To shift the emphasis of care to the beneficiaries – the community
- To ensure access to care and follow-up through a functional referral system
- To integrate a comprehensive care plan into the informal, non-formal and formal health system
- To empower the family/community to take care of their own health
- To empower the client, the carer(s) and the community through appropriate targeted education and training
- To reduce unnecessary visits and admissions to health facilities
- To eliminate duplication of activities and enhance cost-effective planning and delivering of services
- To be pro-active in approach

The goals are very useful for demonstrating the focus of CHBC. However, it is not clear who is responsible for carrying out the actions. Furthermore, some goals are vague, for example, the very first goal uses the word “emphasis,” which is ambiguous, as it can imply any number of possibilities. It can mean “responsibility,” which may not necessarily be a fair situation for the community. To shift “care” to the “beneficiaries” implies that they are no longer “beneficiaries,” because they are required to provide their own care as a community. Another goal speaks of creating a functional referral system and a comprehensive care plan. However, these are not simple objectives and they require the drive of the DoH. Who is to be "pro-active" and initiate the objectives listed which will need to be implemented and sustained? Who will take responsibility for this? Only people with power can "empower," so it appears that the government will need to initiate the process, draw in civil society to take part in it, and then sustain it through leadership and financial support.

2.4.3 Community home-based care stakeholders

The *National Guideline on Home-Based Care / Community-Based Care* also discusses possible roles and responsibilities for the different CHBC stakeholders. It lists the role players in the CHBC "team," which include:

- formal system (doctors, nurses, psychologists, rehabilitation therapists and social workers)
- non-formal system (NGOs, CBOs, FBOs [faith-based organisations] and traditional healers and leaders)
- private sector
- informal sector (families, community health workers, volunteers and caregivers)
- client/consumer (DoH, 2001)

The most obvious role player that is missing from this list is the government, specifically local government. Very often it is the government that provides the stipends to the volunteers and in many cases also the funding to the NPOs that enable them to be sustainable. It can be argued that its role is the most important, especially in its capacity as co-ordinator and legislator. It must be mentioned that the guideline does in fact refer to local government in the preamble to the list of stakeholders. However, by not including it in the CHBC team, it implies that its responsibility is diminished. It mentions that only one organisation should manage the care programme at community level. However, who is responsible for co-ordinating the organisations collectively?

2.4.4 Three pillars of home-based care and community-based care

The *National Guideline on Home-Based Care / Community-Based Care* presents the three pillars of CHBC:

i) Integrated management and referral service organisation

- ii) Training and development of community personnel and professional/technical support personnel
- iii) Integration into the district health system (decentralisation) (DoH, 2001, p. 11)

Identifying these three aspects as being the pillars on which CHBC is built demonstrates the importance that the DoH places on them. Hence, first it is acknowledged that an efficient referral system is crucial for the success of CHBC. Second, the success of CHBC is reliant on community and professional personnel who have been adequately trained to provide quality CHBC. Third, CHBC will only be successful if it is integrated into the district health care system, and this cannot be done without the full support of the DoH and the districts and local municipalities. Based on these three pillars it appears that the DoH has taken the responsibility for the success of CHBC on its own shoulders, through a process of integration. However, it needs to be clarified how this will take place in reality.

2.5 Community home-based care models

A number of CHBC models have been developed since the advent of CHBC. As already mentioned, there are many CHBC organisations in South Africa. However, they are based on many different organisational structures. Adebayo, Irinoye, Oladoyin and Fakande (2004) note that there have been various responses to the AIDS epidemic such as outpatient clinics, outreach care, hospice-care and CHBC that have evolved from government, NGOs, and grassroots groups. Russel and Schneider (2000) identify five general care and support models: 1) Funding, technical assistance, and support programmes; 2) Advocacy and community mobilization; 3) Drop-in centres/support groups; 4) Home-visiting programmes and 5) Comprehensive HBC. On the other hand, Ncama (2005) makes a distinction between 1) service models, which include a) home visiting and b) comprehensive HBC and 2) structural models, which are categorized as a) isolated, b) specialised/private and c) collaborative and integrated. The DoH (2001) also identifies five types of CHBC organisational models. The five DoH models of care or CHBC models are the:

1) Community-driven model;
2) Formal government sector model;

3) Integrated home/community-based care centre model;
4) NGO home/community based care model and the
5) Hospice integrated community home-based care model (ICHC).

This study looks primarily at the community-driven model, the integrated home/community-based care centre model and the NGO home/community-based care model because the focus of the study is on NPOs, which are less formal than government sector models and the ICHC model. These three models are explained briefly below.

2.5.1 Community-driven model

According to Fox, Fawcett, Kelly and Ntlabati (2002), the community-driven model, has, as the name suggests, the local community as the main driver and aims to provide an integrated service, often being attached to a community structure. A designated "community developer" is tasked with collaborating with other organisations and with the training volunteer caregivers (Fox et al., 2002).

2.5.2 Integrated home/community-based care centre model

Structured around a care centre, the integrated home/community-based care centre model is located within the community, usually attached to a church or school, from which it manages its CHBC services (Fox et al., 2002). Although the centre is volunteer-run, the Departments of Health and Social Welfare may send a professional nurse or social worker to assist at the centre (Fox et al., 2002). It should offer various services, such as "pre- and post-test counselling; HIV testing; training of family members and volunteers; distribution of Independent Electoral Committee (IEC) materials; facilitation of income generating projects; supervision and monitoring of community caregivers; conducting of home visits and patient follow-ups, and referral to and from hospital and other service providers" (Fox et al., 2002).

2.5.3 NGO home/community-based care model

The NGO home/community-based care model is similar to the previous one as it is also located in the community where an NGO manages the CHBC programme, identifying needs and providing services (Fox et al., 2002). It can be financially supported by the business and health care sectors, social welfare organisations, or other NPOs, and the CHBC team may include a professional nurse, social worker, project coordinator and volunteers or community caregivers who are based at the NGO (Fox et al., 2002).

The models all indicate that there are a variety of partnerships in each CHBC programme. However, Campbell and Foulis (2004) point out that linkages and partnerships with more powerful groupings and agencies are not always promoted and sustained, and this affects the volunteer caregivers and patients, because, for example, funds are not always available. Such linkages and partnerships are part of the concept of social capital, specifically vertical ties and the greater the number of vertical ties between NPOs and other large professional organisations the greater the chance that the CHBC programme will be sustainable.

The next section will concern itself with caregiving and will discuss the issue of volunteering and the different actors in the caregiving process, namely, the supervisor, the volunteer caregiver and the client. Caregiver activities and the willingness to care will also be discussed.

2.6 Community home-based care in South Africa

One cannot understand the South African CHBC situation unless one understands the South African HIV and AIDS problem and the impact of gender inequality and stigma on the spread of the disease. In addition, the multifaceted problem of poverty also needs to be addressed, as HIV and AIDS is most devastating amongst people caught in the cycle of poverty. Understanding these two aspects is important in order to answer the research question concerning the socio-economic factors affecting CHBC.

2.6.1 AIDS in South Africa

As mentioned in Chapter 1, the Joint United Nations Programme on HIV/AIDS (UNAIDS) estimates that South Africa has between 5.4 and 5.8 million people living with HIV (UNAIDS, 2010). South Africa contains 0.7 per cent of the world’s population, however, 28 per cent of the world’s HIV and tuberculosis (TB) co-infections are found in South Africa, according to the United States Agency for International Development (USAID) (2011). The South African Minister of Health, Aaron Motsoaledi recently stated "all I need to tell you is that we are only 0.7% of the world population, but we are carrying 17% of the HIV/Aids burden of the world. We have the highest TB infection rate per population, and our TB and HIV co-infection rate is the highest in the world, at 73%" (South Africa.info, 2011, para. 9). These high figures demonstrate that South Africa is faced with serious financial and logistical challenges in caring for such large numbers of chronically ill people.

The first official report identifying AIDS cases in South Africa was published in the *South African Medical Journal* in 1983 (Ras, Simson, Anderson, Prozesky & Hamersma, 1983). Hence, the HI-virus has been active in South Africa for almost 30 years, and it continues to maintain a strong hold on South Africa's population.

In 1985, the first black African in South Africa to be diagnosed with HIV was a heterosexual male from the Democratic Republic of Congo (Sher, 1985). Prior to this, it was predominantly white homosexual males who were contracting the virus (Kustner, 1994). Some scholars, such as Illife (2006), argue that infection came into South Africa largely through migrant workers from African countries such as Malawi. Certainly, migration and an itinerant lifestyle has been a major contributing factor to the spread of HIV within the borders of South Africa, and it continues to do so today (Loening-Voysey, 2002). HIV infection amongst black South Africans proved to be devastatingly rapid and in 1987, blood screening revealed that HIV prevalence was doubling every six months (Shapiro, Crookes, & O'Sullivan, 1989). As a result, South Africa began experiencing one of the fastest growing HIV pandemics in the world (Whiteside & Sunter, 2000).

In South Africa, the post-apartheid period carried, and continues to carry, the challenge of reconstruction and development (Loening-Voysey, 2002). The fight against the AIDS epidemic was largely neglected, as the need to address past inequalities was considered to be the government's main priority (Makgoba, 2000). Only after the election of the second democratic government did the HIV epidemic receive greater attention (Heywood, 2005). In 1997, Webb stated that the political response of South Africa to the AIDS epidemic was "one characterised by denial, ministerial wrangling, the misallocation of resources and [was] muted by those forces either resisting or pushing for political transformation" (Webb, 1997, p. 73). In 2004, Cooper et al. declared that in the previous 10 years, the South African government's policy on HIV and AIDS had been "ambiguous at best, often imparting confusing and contradictory messages to health care providers and the public" (p. 78). The above quotes highlight the complacency of the South African government in its approach to HIV, especially early on in the new democracy.

However, things began to change when President Mbeki's government approved the long-awaited provision of free ARV drugs in public hospitals in November 2003, with the expectation that there would be at least one service point in every health district within the year (Baleta, 2003). This change of thinking was largely due to civil society organisations, particularly the Treatment Action Campaign (TAC), playing a decisive role in pressuring the government to act (Cooper, Morroni, Orner, Moodley, Harries, Cullingworth et al., 2004). Deane (2005) argues that the implementation of such a plan depended largely on the wealth of the individual provinces, and did not always take place in reality, as the required infrastructure and management skills were not always in existence at all the service delivery points.

In October 2009, newly elected South African president, Jacob Zuma, announced a new "strategy" to fight AIDS, which was aimed at counteracting the negative impact of the Mbeki era. In his speech to the National Council of Provinces he said:

> We must not lose sight of the key targets that we set ourselves in our national strategic plan. These include the reduction of the rate of new infections by 50%, and the extension of the ARV programme to 80% of those who need it, both by 2011. (Zuma, 2009)

Essentially, it is not a new strategy, but rather a greater commitment from government to implement the objectives of the *National Strategic Plan (NSP) (2007-2011)* (DoH, 2007). President Zuma has explicitly stated his support for the fight against AIDS and he will have to be accountable if the targets set are not achieved. However, most encouraging is the fact that he is publicly supporting the fight against AIDS ("Zuma the architect for HIV/AIDS strategy," 2009).

On World AIDS Day, 2011, President Zuma reiterated the South African government's stance against AIDS and its support for the new *National Strategic Plan to fight HIV, Sexually Transmitted Infections [STIs] and TB (2012-2016).* Two of the strategic objectives have a direct bearing on CHBC, namely:

- To address social and structural barriers to HIV, STI and TB prevention, care and impact
- To sustain health and wellness (Zuma, 2011)

Hence, CHBC has the full support from the South African government because it aims to address "barriers to … care" and to "sustain health and wellness."

2.6.2 AIDS and gender inequality

An added complexity to the problem of HIV and AIDS and the context of CHBC is that gender inequality has played a major role in the spread of HIV. It is estimated that of all the youth in South Africa, those aged between 15 and 24, there are about four females for every male infected with HIV (Dorrington, Bradshaw & Budlender, 2002). This imbalance is partly biological, but it is largely a result of gender inequalities (Cooper et al., 2004). Hence, women are vulnerable to HIV infection not only owing to their anatomy and physiology, but also because of their cultural and socio-economic position (Tlou, 2002). Temmerman, Ndinya-Achola, Ambani and Piot (1995) state that many African women refuse to be tested for HIV, because of the fear of stigma and discrimination, as stigma and discrimination often lead to domestic violence, abandonment or even murder. This means that women fear their husbands or partners, thus illustrating the inequality in male-female relationships. Rape is a sexual assault and is also a means of spreading HIV. Jooma (2005) indicates that women do not have the power to negotiate sexual relationships. A major reason for this being inequalities in income, as women fear "financial reprisal" (Cooper et al., 2004, p. 78).

South Africa has one of the highest numbers of reported rape cases per female population in the world (Christofides, Webster, Jewkes, Penn-Kekana, Martin, Abrahams & Kim, 2003). According to the South African Police Service's (2011) *Annual Report 2010/2011,* the definition of rape has been made much broader, being referred to as “sexual offences” and includes a whole range of transgressions which were never previously regarded as “rape or indecent assault”. The South African Police Service Annual Report of 2007/2008 (which still used the older definition of rape and referred only to women) indicates that between April and December 2008 there were 36,190 reported rapes in South Africa (South African Police Service, 2008). Furthermore, a recent study of 511 women and 487 men in Gauteng Province, South Africa, shows that “overall 25.2% of women had ever had the experience of being raped by a man, whether a husband or boyfriend, family member, stranger or acquaintance while an even higher 37.4% of men admitted to ever raping a woman” (*Gender Links & the Medical Research Council*, 2010, p. 3).

In the context of CHBC, most of the caregivers are women (Ama & Seloilwe, 2011; Akintola, 2006); many of these women are the sole breadwinners (Akintola, 2006) for their families and very often these women are themselves HIV-positive (UNAIDS, 2000a). Demmer (2006) argues that the gendering of caregiving in the context of CHBC is linked to the African social construction of masculinity and femininity. Furthermore, men are often absent from HIV and AIDS-affected homes, as a KwaZulu-Natal study shows, indicating that the men were absent in 72 per cent of the households (only 10 per cent of these were absent due to divorce or separation) with only 34 per cent of the fathers providing for their children (Denis & Ntsimane, 2006). Akintola (2006), referring to the South African situation, stated that traditionally women are expected to do the caring (Ncama, 2005). Therefore, women and girls are bearing the greatest burden of caring for those with AIDS-related illnesses (Cooper et al., 2004).

2.6.3 AIDS and stigma

This section examines the problem of HIV and AIDS and the impact of stigma which often accompanies the disease. Stigma results in discrimination and a fear of discrimination on the part of PLHAs and those associated with them.

Ahn, Grimwood, Schwarzwald and Herman (2003) argue that one of the most challenging aspects of HIV and AIDS is the question of discrimination due to fear, denial and stigmatisation. Furthermore, many women in sub-Sahara African refuse to be tested out of fear of discrimination (Simbayi, Kalichman, Strebel, Cloete, Henda &

Mqeketo, 2007). Therefore, another element affecting the context of CHBC is the issue of stigma as experienced by PLHAs and also those caring for them. According to UNAIDS (2000b), "discrimination refers to any form of distinction, exclusion or restriction affecting a person, usually, but not only, by virtue of an inherent personal characteristic, irrespective of whether or not there is any justification for these measures" (p. 7). Closely linked to discrimination is the concept of stigma. Avert (2011, para. 1) defines stigma in relation to AIDS as follows:

> AIDS-related stigma and discrimination refers to prejudice, negative attitudes, abuse and maltreatment directed at people living with HIV and AIDS. The consequences of stigma and discrimination are wide-ranging: being shunned by family, peers and the wider community, poor treatment in healthcare and education settings, an erosion of rights, psychological damage, and a negative effect on the success of HIV testing and treatment.

As stigma is a socially constructed phenomenon it is not always easy to recognise, and only when stigma is expressed in the form of discrimination does it become more obvious (De Cock, Mbori-Ngacha & Marum, 2002). Stigma results in polarisation, leading to an "us-them" situation and is primarily a result of fear (Skinner & Mfecane, 2004). Stigma often results in the shunning of PLHAs by family, friends, colleagues and even health care workers, with PLHAs even being subjected to various forms of abuse (Herek, Capitanio & Widaman, 2002). Many PLHAs fear being identified as HIV-positive, because of the possible repercussions (Ogden, Esim & Grown, 2004). Hence, at the community level, stigmatisation of PLHAs has discouraged testing and disclosure (Herek et al., 2002; Letamo, 2003; Medley, Garcia-Moreno, McGill & Maman, 2004). The fear is often warranted, as one need only consider the deaths of Gugu Dlamini, in KwaZulu-Natal in 1998 (Martin, 2004), Lorna Mlofane, in the Western Cape, in 2004 (Mbamato & Huisman, 2004), and Isaiah Gobuyo in Kenya, in 2006 (BBC, 2006), who were all HIV-positive, and murdered because of their status.

Whiteside and Sunter (2000) state that the consequences of fear and a culture of non-disclosure result in amongst other things: a reluctance to find out one's sero-status; unchanged sexual behaviour, resulting in the continued spread of the virus through sexual interaction; delayed access to ARVs by PLHAs, making the drugs less effective and speeding up death, and increased mother-to-child HIV transmission, as bottle-feeding (which reduces infant infection) implies a positive status and despite being positive, fear of stigma results in HIV-positive mothers breast-feeding.

Regarding CHBC, Campbell and Foulis (2004) argue that the caregiver’s task is undermined by the stigmatisation of PLHAs, especially when the caregivers are also sometimes viewed as outcasts (Hernes, 2002), becoming the victims of “secondary stigma” (Ogden & Nyblade, 2005, p. 33). Caregivers are under even more pressure when some clients insist on confidentiality and even sometimes try to prevent their caregiver from knowing their status (Maimane, 2004). Skinner and Mfecane (2004) state that family members may also resist being informed of a relative or friend’s HIV-positive status, as they fear that they too may become vulnerable to exclusion, by association, so that this in turn can lead to a “fear of asking for care and a fear of offering care” (p. 162). For this reason many CHBC programmes for PLHAs include the care of patients with other chronic diseases in order to avoid being stigmatised by community members (Akintola, 2004).

There is a great need for human rights law to protect the well-being of PLHAs (Uko, 2004). However, as De Cock, Mbori-Ngacha and Marum (2002) point out, the law can protect PLHAs from discrimination regarding, for example, housing, education or employment, but it is much more difficult to protect them from stigma, which is social and not structural. Disclosure by high profile figures could help to make the disease more acceptable and thus encourage people to find out their HIV-status and also seek counselling and treatment if they are found to be HIV-positive. For this reason, President Bakili Muluzi of Malawi announced that his brother had died from AIDS in 2004, in an effort to remove the secrecy and mystery that surrounds the disease (BBC News, 2004). In 2005, former South African president, Nelson Mandela revealed that his eldest son, Makgatho had died from AIDS (BBC News, 2006).

2.6.4 AIDS and Poverty

This section examines the complex topic of poverty, which is an unfortunate reality for many South Africans. First a short background to poverty in South Africa is presented.

Second, poverty and unemployment are discussed, followed by the third point concerning education and how it relates to poverty. Fourth, a discussion of poverty and how it often results in unhygienic living conditions is presented. Finally, the problem of food security is discussed and how it is affected by poverty.

2.6.4.1 Background to poverty in South Africa

In 2000, former South African president Thabo Mbeki insisted that poverty and not the HI-virus was the cause of AIDS (Mbeki - Africa's challenges, 2000). He was not altogether incorrect, as poverty does indeed play a major role in the spread of any infectious disease, including the HI-virus, although it is not the direct cause of AIDS. According to a Human Sciences Research Council (HSRC) study, 57 per cent of South Africa’s population live in poverty and 72 per cent of the Eastern Cape’s population live in poverty (HSRC, 2004). Landman, Bhorat, Van der Berg and Van Aardt (2003) offer a lower figure suggesting that “most economic and political analysts [state] that approximately 40% of South Africans are living in poverty – with the poorest 15% in a desperate struggle to survive.” Despite being a lower percentage than the percentage presented by the HSRC, the figure still implies that approximately 18 million out of 45 million (based on 2001 census) South Africans are living in poverty. Such dramatic figures demonstrate that the problem of poverty needs addressing as urgently as the problem of HIV and AIDS.

2.6.4.2 Poverty and unemployment

Another crucial factor of poverty is unemployment. According to Statistics South Africa (2011), in the January to March quarter of 2011, there were approximately 4.4 million people in South Africa who were unemployed. Paton, writing for the *Financial Mail* (2010), states that 2.5 million young people aged 18 to 24 are neither working nor in any kind of education or training.

Families who have no breadwinner slip deeper into poverty and in the context of HIV and AIDS this becomes an added burden. If one adds to this the fact that AIDS-related deaths occur primarily in the 25 to 45 year age group (Dorrington et al., 2002) then it is evident that many families’ breadwinners are dying, placing a great deal of strain on dependents, such as children and elderly grandparents (Barnett & Whiteside, 2006).

Furthermore, female breadwinners often have to stop work in order to take care of family members who fall sick, which increases their economic dependence (Cooper et al., 2004).

2.6.4.3 Poverty as it relates to education

Poverty and a lack of education are also closely related. In the context of the AIDS epidemic, education (literacy) levels play a very important role in introducing alternative ways of living and thus leading to a change in behaviour. As Hernes (2002) states, a lack of knowledge has led to a further spread of HIV and AIDS. This is largely due to illiteracy, which in turn affects treatment-seeking behaviours (Ramanathan, Tarantola & Marlink, 2002). Illiteracy and the resultant ignorance also contribute towards the problem of stigma and discrimination (International Center for Research on Women (ICRW), 2002). Stigma in turn leads to delays in treatment (Ogden & Nyblade, 2005).

2.6.4.4 Poverty and unhygienic living conditions

Poverty is often associated with unhygienic living conditions. Such conditions make people living with full-blown AIDS, namely, people who are HIV-positive, but who have a CD4 count of less than 200 (UNAIDS, 2008b) very vulnerable to contracting opportunistic infections. The results of a Kenyan study show that “in informal settlements, poverty and poor living conditions combine to increase the risk environment for HIV infection and other opportunistic infections” (Amuyunzu-Nyamongo, Okeng'o, Wagura, Mwenzwa, 2007, Abstract). Furthermore, poor living conditions make CHBC more difficult, because the work of volunteer caregivers may be compromised. Kang’ethe (2009) noted in his study that poor sanitary conditions are a result of the poverty of the client, the family and the caregivers, and such conditions lead to unhygienic care environments.

2.6.4.5 Poverty and food security

Furthermore, people living in poverty do not have access to quality food. Studies show that opportunistic infections are more common in people with gross nutritional depletion and malnutrition (DoH, 2001). Looked at another way, people with malnutrition are more likely to develop full-blown AIDS if they are HIV-positive. More than 14 million people, or about 35 per cent of the population in South Africa, are estimated to be vulnerable to food insecurity, while 1.5 million children under six have been stunted due to malnutrition (De Klerk et al., 2004). Data from the *South African General Household Survey (2007)* indicate that 10.6 and 12.2 per cent of households had adults and children (respectively) who had gone hungry in the year prior to the survey (Aliber, 2009). PLHAs have higher nutritional needs than normal, healthy people, needing 30-50 per cent more protein and 15 per cent more energy (De Waal & Whiteside, 2003). It is imperative that a person on ARV drugs has a balanced diet for the drugs to be effective (WHO, 2005). Depending on the regimen prescribed, taking ARVs can require dietary restrictions, with some drugs best taken on an empty stomach, while others need to be taken at mealtimes (Food and Nutrition Technical Assistance, 2004). Furthermore, certain foods are able to counteract ARV side-effects (Panagides, Graciano, Atekyereza, Gerberg & Chopra, 2007). Marais (2005) expresses the problem of a lack of food as follows: “When a need as elemental as a square meal goes unmet, the “continuum of care” is effectively robbed of its meaning” (p. 69).

The above discussion emphasises the social complexity of CHBC by highlighting the many overlapping problems which make up the context in which many of the clients, who are cared for by volunteer caregivers, live. Poverty, unemployment, gender inequality and stigma make care and treatment of PLHAs very difficult to implement. Indeed, in a study by Cloete, Strebel, Simbayi, Van Wyk, Henda and Nqeketo (2010) it was found that “in the context of unemployment, poverty, and lower socioeconomic status, HIV status becomes a secondary concern to PLWHA [people living with HIV and AIDS]” (p. 6). Therefore, the challenge of caregiving that volunteer caregivers and their NPOs face cannot be underestimated.

2.7 Volunteering

Wilson (2000) defines volunteering as “any activity in which time is given freely to benefit another person, group, or organisation” (p. 215). Penner (2002) presents a definition of volunteerism as: “long-term, planned, prosocial behaviors that benefit strangers and occur within an organisational setting” (p. 448). According to the *Malawi National AIDS Commission* (2004), “a volunteer is defined as a person who supports your organisation by donating some of their time to provide CHBC services. Such a person may be given incentives, but financial remuneration is not the main compensation that this person receives” (p. viii).

Voluntary work is an important indicator of the willingness of people to take part in activities that will be of benefit to others and the community at large (Harper & Kelly, 2003). As mentioned in Chapter 2, membership in voluntary associations is closely linked to the concept of social capital, and the purposes of voluntary associations are wide and varied (Hall, 1999). Putnam (2000, p. 116) states: “Altruism, volunteering, and philanthropy – our readiness to help others – is by some interpretations a central measure of social capital.” Lin (1999), referring to Putnam, described social capital, as social relations that maintain and encourage voluntary associations and groups. Indeed, without the presence of volunteer caregivers it is inevitable that almost all CHBC programmes would cease to exist.

2.8 Willingness to care

Related to volunteering and an important aspect of caregiving is the caregiver’s willingness to care for a person with a terminal illness. Willingness to care can be defined as a caregiver’s attitude toward providing emotional, physical, and instrumental support to a terminally ill person, especially a PLHA (McDonell, Abell & Miller, 1991). Abell (2001) highlights three important areas concerning a caregiver’s willingness to care: 1) emotional support, which requires caregivers to offer comfort when their client is distressed, or to listen to the client expressing anger or grief, or to be non-judgement regarding their client’s choice of friends or companions; 2) instrumental support, which requires the caregiver to prepare meals, to undertake domestic chores, or to provide transport to medical appointments and 3) physical or nursing support, which requires the caregiver to change soiled bed linen, bath their client, or assist their client in and out of bed.

Abell (2001) identified two separate, but closely connected aspects of caregiving: 1) ability, which concerns the tasks caregivers believe they can carry out if necessary and 2) willingness, which concerns the tasks that they will actually agree to perform. These aspects are separated to differentiate between those tasks caregivers believe, due to their health, resources, or skills that they are actually capable of performing from those they are actually willing to perform (Abell, 2001). Hence, a person may have a recurrent back injury and therefore be unable to perform certain care activities such as transferring a patient from a bed to a chair. However, a person may be physically healthy, but may still be unwilling to assist with physical care out of fear that it may cause a back injury.

The symptoms encountered the most frequently by caregivers, especially when dealing with PLHAs are: diarrhoea, vomiting, thinness, sores in the mouth and/or on the body, frequent fevers, aches and pains, and failure to respond to medicines, severe or very persistent headaches; sweats or chills; pain in mouth, lips or gums; white patches in the mouth; painful rashes or sores on skin or around anus, vagina or penis; nausea or loss of appetite; eye troubles; sinus infection, pain, numbness or tingling in hands or feet; persistent coughing and difficulty breathing or difficulty catching breath (Chimwaza & Watkins, 2004; London, Fleishman, Goldman, McCaffrey, Bozzette, Shapiro & Leibowitz, 2001). Caregivers are expected to respond to the above symptoms in their clients and this list of symptoms helps to put into perspective what kind of symptoms volunteer caregivers need to be willing and able to attend to.

2.9 Main role players in community home-based care

This section discusses the main role players in CHBC, namely the supervisors, the caregivers (who are separated into family caregivers (FCGs) and volunteer caregivers) and the clients who are the recipients of the care provided by the caregivers.

2.9.1 Supervisors

A supervisor, in the context of CHBC, is someone who manages a group of volunteer caregivers. Cameron (2003) states that supervisors should be professional people: with a good understanding of CHBC; who have leadership and organisational skills; who are able to commit the necessary time to the volunteer caregivers; who have experience and an interest in facilitation, mentoring, and counselling; who have access to personal psycho-social support. She identifies the primary roles of the supervisor to be to: "nurture and mentor the caregivers, and identify and address problem areas" (Cameron, 2003, p. 36).

Supervisors also need to have the necessary authority to make and carry out decisions, because they need to gain the respect of the volunteer caregivers and the community (WHO, 2002). However, the WHO's (2002) understanding of a supervisor is slightly different from the understanding of Cameron (2003), because it appears to consider a supervisor to have a much more managerial role in the workings of the CHBC programme. This is largely an issue of semantics, but in this study a distinction is made between a manager of a CHBC programme and a supervisor of a group of volunteer caregivers. It is possible that a nurse could be both a manager and a supervisor if a CHBC programme is very small. Furthermore, there may also be supervisors who are not nurses or retired nurses (Symes, 2006), which is not an ideal situation.

In a study by Rosenberg et al. (2005), supervision is shown to be integral to the success of CHBC programmes, and those programmes that emphasize the need for supervision are also able to assure quality in their CHBC programmes. Butterworth (1992) defines supervision as “an exchange between practicing professionals to enable the development of professional skills” (p. 12). Volunteer caregivers are not professionals, but their supervisors should preferably be nursing professionals who will be able to impart skills to help them develop as caregivers.

Rosenberg et al. (2005) list a range of requirements for successful supervision: regular supervision meetings with caregivers; adequate numbers of nurses to supervise volunteers; visits by a nurse to a new patient's home to plan care; and follow-up visits to homes to ask about satisfaction with care offered. Besides caring for the caregivers under her, the supervisor is also required to visit the clients of her caregivers, which is very important, because it is possible that a caregiver could misdiagnose a client's condition, which could result in delayed treatment and possibly endanger the patient's health (Uys, 2002).

2.9.2 Caregivers

In an American study, Fleishman (1997) identifies six categories of caregiver: 1) nurses; 2) paraprofessionals (nurses' aides and paid helpers); 3) non-nursing professionals (social workers, case managers and therapists); 4) volunteer helpers; 5) non-resident family and friends and 6) co-resident caregivers (household members).

Fleishman’s (1997) study focused on volunteer caregivers who work in close cooperation with the household members of their clients, as this is the purpose of CHBC. In some cases it was the non-resident family or friend who was the volunteer caregiver, therefore in the present study Fleishman’s volunteer helper (category 4) was combined with his non-resident family and friend (category 5), referred to as volunteer caregivers. In this study, the co-resident (household) caregiver (category 6) is labelled FCG. In most cases this FCG is the primary caregiver for the sick person in the home (Uys, 2003a). However, in situations where FCGs have to work (because they are the sole breadwinner), or if they themselves are sick, the volunteer caregiver may become the primary caregiver.

The volunteer caregiver also falls under another category, namely that of community caregiver. According to Uys (2003a), a community caregiver “is a community member who is trained to assist the [primary caregiver] through direct care and support” (p. 4). However, not all volunteer caregivers have been trained, or the training that they have received may not always be adequate. For this reason, one can further sub-divide community caregivers into formal, non-formal and informal caregivers (DoH, 2001). Formal caregivers are Fleishman’s (1997) categories 1-3, who are, for example, nurses, social workers and counsellors. Volunteer caregivers primarily fit into the non-formal and informal categories. In this study, non-formal caregivers are those volunteer caregivers that are affiliated to a CHBC organisation, or an NPO. Informal caregivers are those volunteer caregivers who may be in any one of Fleishman’s (1997) categories 4-6, but who operate independently, in their private capacity, or for example as a church group, but one which is not officially registered with the local government as an NPO. Ogden et al. (2004) refer to this type of care as “unlinked” (p. 3), i.e., it is not linked to any formal care or support service. As they are not affiliated with any care organisation, they are unlikely to have had any formal training. This study’s primary focus is on volunteer caregivers who operate within the ambit of NPOs that manage CHBC programmes, in other words non-formal caregivers.

The FCG falls in the informal caregiver category and FCGs are very important because the volunteer caregivers have to work very closely with them when they are taking care of their clients. The FCG is discussed in more detail in the next section.

2.9.3 Family Caregivers (FCGs)

It is important to remember the role of the primary caregiver, who in most cases is an FCG. Almost universally, families provide the bulk of care and support for PLHAs (UNAIDS, 2004). A description of the care activities that FCGs provide to their sick children, siblings or parents, helps to illustrate the burden that they have to carry on a daily basis. They help with feeding, bathing, dressing, transferring, toileting, and ambulating, and also with instrumental activities such as housework, shopping, cooking, collecting water, transportation to health facilities, and making telephone calls (Akintola, 2008b). FCGs also assist with managing financial and legal affairs, dealing with health or other medical personnel, fetching medication, and caring for the children of the patient and, in the case of death, the deceased (Akintola, 2008b). Furthermore, often the FCG has to care for more than one sick family member and many FCGs are caring for orphans (Lindsey, Hirschfeld, Tlou & Ncube, 2003). In the study by Lindsey et al. (2003), FCGs describe caring for family members with incontinence, diarrhoea, vomiting, confusion, skin lesions, and pain. The study also gives examples of elderly caregivers having to collect wood and water, make the fire, cook, shop, do laundry, clean the house and compound, tend the garden and arable lands, and travel to the health clinic for medication and supplies (Lindsey et al., 2003).

From the above list of care activities, it is obvious that caring for a sick family member, especially a PLHA is not an easy task. Clearly, FCGs need assistance in this regard, because to care for someone on a daily basis for an indefinite period of time will eventually take its toll on the FCGs – physically and emotionally. The availability of community caregivers, specifically volunteer caregivers, is important to alleviate the burden on the FCGs. The following section introduces the volunteer caregiver.

2.9.4 Volunteer caregivers

Campbell, Gibbs, Maimane and Nair (2008) refer to a number of sources, stating that there is an increasing emphasis on the role of volunteer caregivers “in running prevention programmes, providing CHBC, and increasing access and adherence to ARV therapy, especially in sub-Saharan Africa, where there is a dramatic scarcity of health workers.” Most volunteer caregivers are recruited by NGOs (Akintola, 2010) that manage CHBC programmes and train them in basic nursing care (Akintola, 2004), which are volunteer-based, and usually led by an older woman who is often also the founder (Symes, 2006).

NPOs generally have very few paid staff members, with most of the services provided by volunteers who may or may not be paid a stipend (Russel & Schneider, 2000). NPOs also have only a few care professionals, whose primary role is to supervise and train the volunteers (Akintola, 2004). It is important to keep in mind that all NPO care services are provided free of charge (Nsutebu, Walley, Mataka & Simon, 2001) to the clients and their families. NPOs invest a great deal of time and money in their volunteers, especially in the form of training (Uys, 2003a). Therefore, volunteer caregivers are equipped with new skills and the increased confidence that comes from training makes them better equipped to care for their clients (Green, Dhaliwal, Lee, Nguyen, Curtis & Stock, 2003). However, it also opens up opportunities for them in the job market and as many volunteer caregivers are unemployed, it is likely that they will leave their volunteer work and take up employment when the opportunity arises (Defilippi & Cameron, 2010; Fox et al., 2002). Unfortunately, the time and money invested in volunteer caregivers are then lost when they leave the NPO and the cost is irreplaceable, as community caregiving is not a profit-making exercise. Sometimes volunteer caregivers simply stop volunteering, or sometimes they are unreliable and this makes “recruiting and maintaining committed and motivated volunteers” a major challenge for NPOs (Russel & Schneider, 2000, p. 32).

Volunteers need to be compensated for the work they do (Cullinan, 2000), as their service is extremely valuable to the community. However, if NPOs are able to provide their volunteer caregivers with stipends, they find it very difficult to sustain such payments over a long period, because, as mentioned, there is no profit or cost recovery for CHBC programmes (Russel & Schneider, 2000; Nsutebu et al., 2001). Indeed, volunteers in a study by Boros (2010) complained about the irregularity of the stipend payments rather the actual amount. The sustainability of CHBC programmes is thus highly dependent on the use of volunteers to help defray costs (Abdool Karim et al., 2002; Uys, 2003a). Volunteers with a strong commitment and a generous, non-judgemental spirit are essential if CHBC is to become a sustainable reality (Anderson, 1994). Russel and Schneider (2000) note that there are certain non-financial incentives that can be used to help to retain volunteer caregivers: 1) a sense of belonging; 2) a supportive work environment; 3) opportunities to gain skills and 4) passing a rigorous screening process.

Uys (2003a) also identifies the ethical dilemma of recruiting volunteer caregivers who are themselves living in poverty and using them to serve others, but without remuneration or some form of compensation. There is a danger that they can be exploited, because they may be volunteering in the hope that they will find work. Therefore, volunteers need to be given some form of material compensation for their efforts (Cullinan, 2000).

It is also important to sustain serial caregivers, in other words those volunteers who provide care to a number of PLHAs over time. As experienced caregivers, they are doubly valuable, because they have acquired care skills and knowledge concerning AIDS and the local health care system (Leblanc, London & Aneshensel, 1997). Indeed, caregivers constitute a national health resource and they should be treated as such (Benjamin, 1988).

2.9.5 Clients

As mentioned in Chapter 1, CHBC is targeted at a wide of variety of people (DoH, 2001). However, one of the primary targets is PLHAs and one of the greatest burdens to a diagnosis of HIV and AIDS is severe stress, which often results in the PLHA developing depression and anxiety (Coetzee & Spangenberg, 2003). Hence, as soon as a person is diagnosed with HIV, he or she will require counselling and teaching, and as the disease progresses, nursing care will be required (Uys, 2003a). Hence, PLHAs and their FCGs will require a wide variety of services including “effective interpersonal communication, psychosocial support … shared confidentiality … bereavement counselling and anticipatory guidance” (Lindsey et al., 2003, p. 499). Counselling skills are needed to heal family relationships and also to facilitate funeral arrangements (Kikule, 2003). A study of terminal cancer patients in Kenya and the United Kingdom (UK) found that the main concern for the African participants was for pain control and analgesia (Murray, Grant, Grant & Kendall, 2003).

A study by Steinberg, Johnson, Schierhout and Ndegwa (2002) illustrates the condition of many of the clients who are being cared for by FCGs and volunteers:

- One in six of AIDS-sick individuals in the households surveyed could not control their bowels and about the same number could not control their bladders.
- About 20% could not wash without assistance.
- Households reported that on average the AIDS-sick person was chronically ill for a year before dying.

Steinberg et al. (2002) note that 30 per cent of the participants (n=71) in their study had lost all income due to illness, resulting in acute financial needs. This aspect of care is very difficult for volunteer caregivers to deal with as they are often poor themselves and they cannot always give their clients the material support they need, which in turn affects quality care (Kang'ethe, 2009). The following section looks at the volunteer caregivers and the different kinds of care activities or services that they provide for their clients.

2.10 Volunteer caregiver activities

This section discusses the caregiving activities that volunteer caregivers have to undertake. Volunteer caregivers assist FCGs and clients with aspects such as hygiene, wound care and symptom control with a view to improving the quality of life of the client and family by: 1) making the client more comfortable; 2) improving the health of the client and 3) lightening the care load on the FCG (Uys, 2002). Care activities can be placed into four broad categories: instrumental care; personal care; counselling and spiritual support and health education.

2.10.1 Instrumental care

Instrumental care refers to the daily chores that are required in the running of a household (Lindsey et al., 2003). Volunteer caregivers are often required to undertake such chores, because their patients are sometimes too sick to carry out basic household activities. In a Norwegian home care study by Bunch (1998), the following instrumental categories were identified: cleaning/laundry, meal preparation and eating, shopping and activities of daily living. Instrumental activities in rural areas include collecting water and wood, cleaning, shopping, cooking, and dealing with finances (Lindsey et al., 2003). Volunteer caregivers also sometimes assist with transportation, making telephone calls, visiting health facilities and the procurement of medication (Akintola, 2006, 2004).

2.10.2 Personal care

The following activities can be described as personal care, namely, bathing, feeding, dressing, mobilizing, and helping with elimination (Lindsey et al., 2003). In addition, caregivers provide basic nursing care, including mouth care, cleaning pressure sores, skin care, turning bedridden patients (Akintola, 2006).

All caregivers are expected to use universal precautions in their work including hand-washing, cleaning linen with soap and water, using disinfectants and detergents, burning or safely disposing of rubbish and avoiding contact with blood or body fluids by using gloves and diapers (WHO, 2002). A study by Lindsey et al. (2003) indicates that although the caregivers were advised on the use of universal precautions, very few caregivers heeded this advice. As one FCG explained, “It is my daughter, I love her. I can’t wear gloves or other things. If I am holding or nursing my child I love, putting a barrier would be like I don’t love her” (Lindsey et al., 2003, p. 495).

2.10.3 Counselling and spiritual support

Besides the general categories of instrumental and personal care activities, volunteer caregivers also provide the following services: counselling and health education (Akintola, 2004). According to the *National Home-Based Care Programme and Service Guidelines* of the Kenyan Ministry of Health (2002), counselling can be described as a professional helping relationship that assists people to understand and deal with their problems. The mental health of ill people, family members and members of the CHBC team is vitally important (WHO, 2002). Furthermore, according to Akintola (2006) volunteer caregivers provide spiritual support by praying with their patients and moral support by showing them love and compassion, and by talking and listening to them (Akintola, 2006).

The following section is based on the *National Home-Based Care Programme and Service Guidelines* (Kenyan Ministry of Health, 2002). Counselling includes psychological/emotional support, anxiety reduction, promotion of positive living, and help with making informed decisions about HIV testing, life and living. Good counselling also involves: accurate information about the subject, active listening, self-awareness and an understanding of the counselling process. In the context of CHBC there are several types of counselling: 1) Pre- and post-test counselling—voluntary counselling and testing (VCT); 2) Behaviour change counselling; 3) Group counselling; 4) Family counselling; 5) Supportive counselling; 6) Crisis counselling; 7) Spiritual/pastoral counselling and 8) Death and bereavement counselling (Kenyan Ministry of Health, 2002). It must be noted that VCT has since been replaced by HIV counselling and testing (HCT) (Skinner, 2010).

The objectives of counselling and psycho-spiritual care in CHBC are to:

- Control the spread of HIV/AIDS through information dissemination, promotion of safer sex, advocacy for behaviour change, and encouragement of better health-seeking behaviour.
- Help PLHAs to come to terms with the infection and to adopt a positive living attitude.
- Help the client/PLHA make well informed decisions about sex and sexuality.
- Offer psychological and spiritual support to PLHAs and their families.
- Help PLHAs to assess and talk about what their life has meant to them through their belief systems, whatever they may be.
- Help PLHAs accept the need to talk to family members about their condition and future plans (Kenyan Ministry of Health, 2002, pp. 14-15).

Counselling/psycho-spiritual care requirements and issues include: 1) confidentiality; 2) acceptance; 3) training; 4) monitoring and supervision and 5) a multi-sector approach and collaboration/networking (Kenyan Ministry of Health, 2002, p. 15).

However, the provision of emotional support to their clients is a difficult task for volunteer caregivers especially if they do not have the necessary support themselves and which may lead to caregiver burnout (WHO, 2002).

2.10.4 Health education

Volunteer caregivers also offer advice and teach FCGs and their patients basic skills on how to grow vegetable gardens for subsistence and give advice regarding adequate nutrition and monitor drug adherence (Akintola, 2006). Volunteer caregivers also provide Directly Observed Treatment, Short Course (DOTS) for those who are on TB medication. They may not prescribe or administer any drugs, but they can refer serious cases to the health facilities (Akintola, 2004; Akintola, 2006).

The preceding section discussed the caregiving activities of volunteer caregivers with specific reference to instrumental care, personal care, counselling and spiritual support, and health education. The following section presents monitoring and evaluation in CHBC.

2.11 Monitoring and evaluation

There is a great need for improved evaluation in the area of HIV and AIDS treatment, care and support. This is evident from the national *HIV and AIDS and STI Strategic Plan for South Africa, 2007-2011*, which recognises monitoring and evaluation as an important policy and management tool (DoH, 2007). According to the NSP (2007-2011), the lack of a comprehensive monitoring and evaluation framework and clear targets and responsibilities was a major weakness of the NSP 2000-2005 (DoH, 2007). The NSP (2007-2011) identified the need for the establishment of a monitoring and evaluation plan for all civil society structures.

In addition, the DoH (2001) *National Guideline on Home-Based Care / Community-Based Care* places an emphasis on the evaluation of CHBC. It states that the recommendations that are derived from the evaluation process are an essential component of the development and provision of on-going care (DoH, 2001). According to Van Praag and Tarantola (2001), there is still a great deal to be done in terms of the evaluation and monitoring of care provided to PLHAs.

The Kenyan *National Home-Based Care Programme and Service Guidelines* (Kenyan Ministry of Health, 2002), identified one of the constraints or limitations of monitoring and evaluating CHBC to be the inability of NPO CHBC programmes or organisation to formulate monitoring and evaluation tools for the collection of data. Furthermore, the coverage and effectiveness of the majority of the CHBC programmes that are in operation remain unknown, as very few have the resources or the capacity to monitor or evaluate their activities (Ogden et al., 2004).

Monitoring and evaluation of CHBC programmes is important to ensure adequate and effective care, and the WHO (2002) has highlighted the following characteristics of monitoring: First, the monitoring process is generally undertaken by a supervisor who is usually a qualified nurse. Monitoring care activities may involve conducting site visits in order to assess care and to promote peer supervision. Furthermore, it is important to monitor the accessibility of vital medication, supplies and equipment. Included in the monitoring process is the need to keep statistics on the numbers of sick people who access CHBC and their diagnosis and treatment regimens. Also included is the need to monitor CHBC education of staff. Finally, the WHO notes that financial accountability and budget management is also an important part of monitoring and evaluation (WHO, 2002).

The preceding section presented the issue of monitoring and evaluation with specific reference to CHBC. It highlighted the importance that the South African government places on the process of monitoring and evaluation. The following section discusses the importance of training in CHBC.

2.12 Training

Volunteer caregivers need adequate training, as they are responsible for guiding family members to care for chronically ill patients. Therefore, they need to be well prepared to handle a range of medical problems as well as psychological challenges such as bereavement counselling (Cullinan, 2000). Caregivers need to be trained to undertake the cleaning and dressing of wounds, provide oral hygiene, to supervise the taking of medication and be able to diagnose opportunistic infections (Ncama, 2005). Cameron (2003) recommends that training courses need to provide volunteers with a wide range of knowledge and skills so that they will be equipped to provide quality holistic care and support. Indeed, Ncama (2005) stated that insufficient knowledge among volunteer caregivers was identified as the primary cause of poor quality care.

Thabethe (2006, pp. 32-33) noted that the average CHBC training course comprises the following training aspects:

- Overview of the role of community home-based caregivers
- Sexually Transmitted Diseases (STDs)
- Tuberculosis (TB) in the context of HIV and AIDS, HIV and AIDS in context, caring for someone living with HIV and AIDS, death and dying
- Basic nursing skills, palliative care, pain and symptom control, psychosocial and spiritual support, helping the patient with his or her feelings
- The body anatomy, nutrition, feeding
- Basic communication, presentation skills.
- Paediatric issues and family care
- Caring for the caregiver
- Toilet care, environmental hygiene and bed-making
- Dressing and undressing, personal hygiene
- Wound care, administering medicine
- Caring for patients with infectious diseases

Callaghan, Ford and Schneider (2010) highlighted the importance of on-going training for caregivers and they reported that South African community health workers reported a desire for better training and supervision in order to meet the challenges that come about with CHBC. In a study by Schneider and Lehmann (2010), they note that there is no standardized training.

2.13 Benefits of community home-based care

The following section presents the benefits of CHBC. First, the cost of CHBC is discussed, followed by the benefits of CHBC to families and FCGs. Thereafter is a discussion of the benefits of CHBC to clients who are terminally ill. Finally, the benefits of CHBC to the volunteers themselves are discussed.

2.13.1 Cost of community home-based care in relation to clients

From the perspective of the client and the FCGs, it can be argued that one of the benefits of CHBC is that it is less expensive for the family, because the cost of transport to a hospital and the time spent on hospital visits is reduced (Rosenberg et al., 2005; Uys, 2003a). According to Jagwe and Barnard (2002), CHBC is cheap and acceptable to the family and patient and can offer care that respects cultural practices and removes the need for family attendance at hospital (Harding & Higginson, 2005; Merriman & Heller, 2002). Furthermore, CHBC allows relatives to take care of the client while attending other household duties (Uys, 2003a).

From the perspective of public health care institutions, one of the benefits of CHBC is that the totality of care is less expensive, since time spent in hospital by AIDS patients is reduced (Anderson, 1994; Uys, 2001; Uys, 2003a). The DoH *National Guideline on Home-Based Care / Community-Based Care* (2001) states that CHBC will, “reduce and share the cost of care within the system” (p. 9). However, it is debatable whether the “sharing of the cost” of care actually benefits the patients and their families or whether it primarily benefits the DoH. It is also questionable if the so-called “sharing of costs” is spread evenly between the DoH and the clients or indeed whether it should be spread evenly at all considering that most people accessing CHBC are living in poverty.

2.13.2 Family and community home-based care

A major benefit of CHBC, for family and friends, is that they are always close by to give support and to provide continuous, individualised care (Kikule, 2003; Uys, 2003a). Clients often feel that the care received through CHBC programmes is adequate, and there is a sense of privacy (Kikule, 2003). Clients who are suffering often see their home as a safe place containing the relationship between them and their family, where they can feel free to express their feelings of distress, which can be therapeutic for the patient (Regnard & Tempest, 1998). Research has shown that many people prefer to receive care in familiar environments close to family and friends and within their own community (Anderson, 1994; Kikule, 2003; Uys, 2003a). The DoH *National Guideline on Home-Based Care / Community-Based Care* (2001) also promotes the fact that CHBC “allow[s] people to spend their days in familiar surroundings and reduce[s] isolation” (p. 5).

Furthermore, effective CHBC has been shown to improve the quality of life of patients, as well as that of their primary caregivers. For families, CHBC may prove more convenient and less expensive than transporting sick family members to the hospital. CHBC also provides opportunities for HIV and AIDS education, which is particularly important for more isolated communities (WHO, 1993). According to a Brazilian study, when dealing with medication, CHBC can in fact improve adherence to ARVs (Gupta, Santos da Silva & Passos, 2005).

2.13.3 Dying and community home-based care

CHBC has been widely acclaimed as having many advantages, including improving the experience of illness, dying and death for PLHAs and their families alike (Campbell & Foulis, 2004; DoH, 2001; Nsutebu et al., 2001; Uys, 2001; Uys, 2003b; WHO, 2002). According to Uys (2003b), "the relationship between dying at home and having a 'good' death supports the notion that CHBC is the model of choice for PLHA [people living with HIV or AIDS]" (p. 279). From the perspective of bereavement, CHBC allows the client and the family time to come to accept the illness and inevitable death of the client (Uys, 2003a). Furthermore, Uys (2003a) argues that many people prefer to handle their illness and mortality in surrounding that are familiar to them rather than in a hospital environment. It is also argued that CHBC can also be more beneficial for terminally ill patients, where they are in a supportive home environment, and where they may die surrounded by family and friends (Cullinan, 2000). Studies show that between 50 and 70 per cent of patients with terminal illnesses would prefer to remain at home for as long as possible until their death (Townsend, Frank & Fermont, 1990). In a study of 300 Scottish nurses, it was found that 80 per cent of them would choose to die at home if it were possible (Doyle, 1982). In relation to terminal care, eight elements make up a 'good death', namely: comfort, openness, completion, control, optimism, readiness, and choice of location (Mak & Clinton, 1999).

2.13.4 Caregiver satisfaction and community home-based care

Related to the benefits of caregiving outlined above is the satisfaction of this work from a caregiver's perspective. Horsman and Sheeran (1995) state that caregivers have reported the following sources of satisfaction: providing non-judgemental care to a stigmatised population, providing comfort and support, friendships with patients, providing education, helping family members and friends, and receiving positive feedback from patients and their families. Additional sources of satisfaction are when volunteers experience a sense of organisational commitment, supportive supervision, job involvement, effectiveness, fulfilment and self-respect (Gysels, Pell, Straus & Pool, 2010; Demmer, 2002; Gimbel, Lehrman, Strosberg, Ziac, Freedman, Savicki & Tackley, 2002).

The perceived rewards of HIV and AIDS caregiving can serve as a buffer against burnout, and administrators have been encouraged to help employees identify the rewarding aspects of their jobs and to develop ways to maximise the benefits of this type of work (Bennett, Ross, & Sunderland, 1996; Demmer, 2006). Ferrari, McCown and Pantano (1993) note that caregivers experience personal joy, fulfilment, and pleasure from providing social support to their patients, but as the PLHA’s illness progresses, these caregivers report discomfort, distress, and sorrow. Hence, caregiving can be a bitter-sweet occupation.

The preceding section presented the benefits of CHBC. It looked at the cost of CHBC, the benefits of CHBC to families and FCGs, the benefits of CHBC to clients who are terminally ill and finally, the benefits of CHBC to the volunteers themselves.

2.14 Disadvantages of community home-based care

The following section discusses the disadvantages of CHBC. First, the financial costs of CHBC are discussed followed by a discussion of the “hidden costs”. Thereafter, the burden of caregiving is discussed in some detail.

2.14.1 Financial costs of community home-based care

It appears that the primary reason for the emergence of HBC/CHBC in the USA, one of the first countries to begin HBC/CHBC, as a result of the AIDS epidemic, was cost-related (Spier & Edwards, 1990). However, not everyone is in agreement concerning the costs of CHBC (Haile, 2000; Hansen, Woelk, Jackson, Kerkhoven, Manjonjori, Maramba et al., 1998; Russel & Schneider, 2000). However, as Nsutebu et al. (2001) indicate, CHBC is often the only available option to PLHAs, when hospital care is unaffordable and inaccessible. Indeed, the South African government considers CHBC to be a means to reduce hospital costs (DoH, 2001). Cost has certainly been an issue for the South African government with regard to the care of PLHAs, and this is borne out by its reluctance, in the past, to spend money on ARV treatment (Baleta, 2001). As mentioned earlier, the DoH (2001) lists a number of reasons why the government chose to develop a CHBC strategy for the country: shortage of hospital beds; an inadequate number of medical, nursing and allied health professionals in the public sector; lack of resources for treatment and drugs; increasing demands of curable conditions on existing institutional care; hospitals, which are crowded and over-stretched, are often unsuitable for managing patients with terminal or long-term diseases and cost of institutional care. It is evident that the first five reasons are actually a result of the last, namely the cost of institutional care. Owing to the costs of hospitalisation, the government needed to find an alternative source of care, in the context of the AIDS epidemic, and it looked to CHBC programmes to do this. However, as Russel and Schneider (2000) note, evaluations in various African countries reveal that CHBC is not necessarily a “quick fix and cheap alternative to hospital-based care” (p. 328). Rugalema (2000) points out the danger that governments and development agencies may be tempted to use the idea of community resources (i.e. CHBC) as an excuse to do nothing or very little, to alleviate the effects of AIDS on all those affected by the disease. Cullinan (2000) expresses this more forcefully: “[I]f state health facilities are simply going to discharge AIDS patients and assume that they will be cared for ‘at home’, HBC will simply be a brutal form of privatisation where the poorest communities are expected to bear the greatest burden of the epidemic” (p. 3). Furthermore, Marais (2005) adds that the major weakness of CHBC is the fact that institutional support is lacking and inconsistent.

The monetary costs involved in CHBC include: the cost of travelling (taxi or bus fare, or paying for petrol); the cost of food; the cost of medical supplies including medicines and the cost of consulting with traditional healers (Hansen et al., 1998; Nsutebu et al., 2001). Such costs could either be the burden of the client, the FCGs or the volunteer caregiver. Indeed, all three could contribute at any time to these costs, but more importantly the health institutions are spared. Marais (2005) notes that CHBC is not cheap, but only “appears that way because the true costs are hidden, deflected back into the communities and domestic zones of the poor” (p. 67). The following section discusses the hidden costs of CHBC.

2.14.2 Hidden costs

CHBC contains certain hidden costs (Leblanc et al., 1997) such as “time,” and this mainly affects the caregiver (either the FCG or the volunteer caregiver): time spent caring; time spent travelling to hospitals and clinics to collect medicines; time spent visiting the clients and time spent buying food and supplies (Nsutebu et al., 2001). In Hansen et al.’s (1998) study, it is pointed out that 2.5-3.5 hours per day are spent by caregivers (the study is not clear which caregivers, whether family or volunteer caregivers) on routine patient care. This is a substantial amount of time away from normal activities and potential economic activities. Time is money and indeed if one spends time on something, especially a service, then there should, in a just world, be some form of compensation.

Hence, caregiving activities are time consuming, because very sick patients cannot be left alone (Chimwaza & Watkins, 2004). Caregiving affects the social life of caregivers, especially FCGs, as the work often prevents the caregiver from visiting friends and attending social events, such as funerals (Chimwaza & Watkins, 2004).

Another “cost” that is not always considered is the health of the caregiver, whether a FCG or a volunteer caregiver. The psychological health of the caregiver can be adversely affected by strain, stress and depression (Leblanc et al., 1997). Therefore, the following section looks at the burden of caregiving.

2.14.3 Burden of caregiving

Marais (2005) states that, “expecting the poor to provide the backbone and lifeblood of care – with a minimum of structured support – is unreasonable and unrealistic” (p. 67). Governments should not allow the burden of care to rest on communities without the necessary support structures. According to Wainwright (2002), CHBC caregivers experience greater stress than medical caregivers and Wainwright argues that this is due to a lack of adequate training, mentoring and support. Caregivers are undermined by the traumatic physical and psychological effects of caring for the terminally ill, resulting in burnout and exhaustion (Lindsey et al., 2003).

A Ugandan study points to the emotional challenges facing carers of children with AIDS, children who might already have witnessed their parents “fall sick, become incapacitated, lose their jobs, become stigmatised and die” (Sayson & Meya, 2001, abstract, p. 541). Caregivers suffer from the emotional consequences of their inability to provide for their clients as they would like to, and from their clients’ failure to improve (Chimwaza & Watkins, 2004).

Furthermore, the majority of the caregivers complain of the physical strain – “taking the patient in and out of the house” – painful hips from sitting in one place watching the patient and washing soiled sheets (Chimwaza & Watkins, 2004, p. 801). In an American study, PHLAs’ problem behaviours, caregiver work strain and unemployment are strongly associated with greater symptoms of poor health in caregivers (Leblanc et al., 1997). Caregiver depression is an especially important correlate of poor physical health among all caregivers (Leblanc et al., 1997). Respondents in a Botswana study also reported that elderly caregivers experienced depression and personal neglect (Lindsey et al., 2003).

Another interesting finding by Leblanc et al. (1997) suggests that many caregivers to PLHAs go about the task of care provision while suffering substantial sickness, discomfort and pain of their own while caregivers of all ages describe a sense of loneliness and isolation, as the sheer burden of work keeps them within the house and compound (Lindsey et al., 2003). Linked to this and owing to the nature of HIV and the difficult conditions in which many clients live, FCGs often have HIV or AIDS themselves (Leblanc & Wight, 2000). Thus, these caregivers have a greater risk of developing health problems. PLHAs who are also caregivers are susceptible to contracting the opportunistic infections that their patients might be carrying. Furthermore, in addition to physical health difficulties, they also experience psychological stress, as discussed by Leblanc and Wight (2000). Ferrari et al. (1993) state that studies have shown that PLHAs who are volunteer caregivers show emotional and psychological strain, which are linked to perceptions of personal vulnerability to HIV, negative effects on their own social networks, and concerns regarding the possible loss of a valuable, intimate relationship with the patient. PLHAs who are caregivers display greater anxiety, depression, anger, and helplessness (Ferrari et al., 1993).

To protect themselves, caregivers may develop professional detachment and may need to see individual clients as different from themselves, to avoid thinking about their own vulnerability to death. Avoidance or negative attitudes toward clients (for whatever reason) are likely to be matched by a decline in quality of care. Caregivers who are uncomfortable discussing death may become insensitive to the needs of clients, thus depriving them of the opportunity to deal with their own mortality. If caregivers are not vigilant, their own grief and unresolved feelings about death can interfere with the goal of providing a safe and accepting environment for the expression of grief (Demmer, 2006).

Volunteer caregivers often have multiple-caring commitments, as besides their work assisting FCGs and their clients, many volunteers are caring for their own family members, or their neighbours (Akintola, 2006). Hence, FCGs (Kang'ethe, 2010a) and volunteer caregivers frequently experience burnout (Cox, Pakenham & Cole, 2010). Burnout is described as "a process in which every day stresses and anxieties that are not addressed gradually undermine the carer's mental and physical health, so that eventually care giving and personal relationships suffer" (UNAIDS, 2007, p. 5). Burnout can be reduced by building in support sessions, ensuring recreational breaks, rotating staff and through the support of friends, spiritual leaders, neighbours and community volunteers (WHO, 2002).

Caring for someone in the terminal stages of an illness places tremendous strain on all involved. Everyone is impacted, from family and friends to health and social service workers and those in the community, such as community volunteers. Volunteers need regular debriefings as the work that they do is draining and can be very depressing (Cullinan, 2000).

The above section discussed the disadvantages of CHBC, including burden of the financial costs of CHBC, the "hidden costs" of CHBC and a general discussion of the burden of caregiving. The following section is a discussion of quality CHBC.

2.15 Quality community home-based care

This section presents the concept of quality CHBC using various sources dealing with quality CHBC. Sources referred to included documents from the WHO, UNAIDS and USAID. In addition, the *Batho Pele* Principles are also referred to and also certain DoH documents.

The South African Department of Public Service and Administration (DPSA) developed a guide entitled: *Batho Pele Handbook on Service Delivery* (DPSA, 2003) which explains *Batho Pele* as follows:

> Simply stated, Batho Pele is an initiative to get public servants to be service orientated, to strive for excellence in service delivery and to commit to continuous service delivery improvement. It is a simple, transparent mechanism, which allows customers to hold public servants accountable for the type of services they deliver. (p. 8)

The WHO (2006) document entitled: *Quality of care: a process for making strategic choices in health systems* argues that there is a need to focus on quality in health systems at this time. It states that: “Even where health systems are well developed and resourced, there is clear evidence that quality remains a serious concern … with wide variations in standards of health-care delivery within and between health-care systems.” Furthermore, it states that: “… the process of improvement and scaling up needs to be based on sound local strategies for quality so that the best possible results are achieved…” (WHO, 2006, p. 3). This last statement referred particularly to developing countries like South Africa. Hence, in both developed and developing countries there is a need to determine what quality is and to achieve this quality in all health care systems.

The WHO (2006) document addresses the issue of quality care in health care systems by suggesting that health care needs to be:

- ***effective***, delivering health care that is adherent to an evidence base and results in improved health outcomes for individuals and communities, based on need; According to the USAID (n.d.) document entitled: *Institutionalizing quality in health services*, “the quality of health services depends on the effectiveness of service delivery norms and clinical guidelines" (p. 4). For example, when a volunteer caregiver provides the client with a bed bath, is it done with dignity? Is the client washed properly? Does the volunteer caregiver use universal precautions?

- ***efficient***, delivering health care in a manner which maximizes resource use and avoids waste; "The efficiency of health services is an important dimension of quality because it affects product and service affordability and because health care resources are usually limited" (USAID, n.d., p. 5; Franco, Silimperi, Veldhuyzen van Zanten, MacAulay, Askov, Bouchet & Marquez, 2002). In the case of CHBC, the clients do not pay for the services that they receive. However, from the point of view of the CHBC management and also the donors or funders, supervisors and volunteer caregivers should refrain from wasting resources.
- ***accessible***, delivering health care that is timely, geographically reasonable, and provided in a setting where skills and resources are appropriate to medical need: "Access to services reflects a lack of geographic, economic, social, cultural, organisational, or linguistic barriers to services" (Franco et al., 2002, p. 9). As CHBC takes place in the home, this aspect of quality is somewhat different to institutional access. It would rather cover the following: How freely available are the volunteer caregivers to their clients? Do they speak the same language as their clients? Do they visit their clients on a regular basis? Do they live close to their clients?
- ***acceptable/patient-centred***, delivering health care which takes into account the preferences and aspirations of individual service users and the cultures of their communities;
- ***equitable***, delivering health care which does not vary in quality because of personal characteristics such as gender, race, ethnicity, geographical location, or socioeconomic status;
- ***safe***, delivering health care which minimizes risks and harm to service users. (WHO, 2006, p. 9-10). "As a dimension of quality, safety means minimizing the risks of injury, infection, harmful side effects, or other dangers or related to service delivery" (USAID, n.d., p. 5; Franco et al., 2002). Volunteer caregivers need be trained by professionals to ensure that they do not cause their clients any

harm. In the case of CHBC, harm refers to both physical harm and psychological harm. Universal precautions which were outlined earlier need to be implemented.

The USAID (n.d.) document already referred to above and the document by Franco et al. (2002) entitled: *Sustaining quality of healthcare: Institutionalization of quality assurance*, identify a similar set of key dimensions by which to view the concept of quality, specifically in the context of health care. The document by Franco et al. (2002) includes a number of the dimensions that were included in the WHO (2006) document on quality care, namely, effectiveness, efficiency, accessibility and safety, which were included with the WHO (2006) dimensions in the above paragraph. However, in addition to these common areas, the USAID document also addressed the following dimensions of quality care:

- ***technical competence:*** "Technical competence refers to the skills, capability, and actual performance of health providers, managers, and support staff" (USAID, n.d., p. 4). Hence, a volunteer caregiver needs to have the skills and knowledge to provide personal care such as giving a patient a bed bath. A supervisor would also need the correct training to provide adequate supervision;
- ***interpersonal relations:*** This category refers to the interpersonal relations between the various role players in the care continuum. The USAID (n.d.) document states that, "Good interpersonal relations establish trust and credibility through demonstrations of respect, confidentiality, courtesy, responsiveness, and empathy" (p. 5). The four main actors in the caregiving process are the client, the FCG, the volunteer caregiver and the supervisor. It is very important that the volunteer caregivers are able develop trust and credibility in their relationships with their clients and their FCGs. As mentioned in Chapter 2, social capital is closely linked to the concept of trust;
- ***continuity:*** "Continuity means that the client receives the complete range of health services that he or she needs, without interruption, cessation, or unnecessary repetition of diagnosis or treatment" (USAID, n.d., p. 5). CHBC services are not as comprehensive as those offered by a health care institution. However, volunteer caregivers need to visit regularly to ensure the clients are

taking their medication and that there are no other symptoms that may need treatment. The volunteer caregivers' supervisors should also visit the clients so that their professional training and experience can be put to use in case the volunteer may have missed a particular symptom that may need urgent treatment;

- ***amenities:*** As CHBC takes place in the clients' homes, amenities do not refer to the same facilities and features that make a patient's visit to a health care institution more satisfactory (USAID, n.d., p. 5). However, they could well refer to the professional appearance of the volunteer caregivers and supervisors.

The document by Franco et al. (2002) adds a ninth dimension, namely,

- ***choice of services:*** This dimension refers to the clients' freedom to choose, for example, their care provider or what treatment they are given. An important aspect of this dimension is access to information to make an informed choice.

When examining a concept such as quality care, other related concepts such as standards of care and best practice must also be looked at. Essentially, in order to determine whether something has "quality" it is necessary to measure it against a standard that is recognized nationally or internationally. An example of a broad standard, which is used throughout South African governmental structures, including health care, is the eight *Batho-Pele Principles* (DPSA, 2003). The second principle is titled: "Setting service standards." This principle is further elaborated as follows:

> This principle reinforces the need for benchmarks to constantly measure the extent to which citizens are satisfied with the service or products they receive from departments. It also plays a critical role in the development of service delivery improvement plans to ensure a better life for all South Africans. Citizens should be involved in the development of service standards. (North West Development Corporation, n.d., p. 6)

As indicated by the DoH (2001), CHBC is an important aspect of the overall health care system of the South Africa. Therefore, "quality" CHBC also needs to be viewed as an important characteristic of this greater system of care. The need for quality CHBC is emphasized in the guideline itself, where it states that one of the principles of CHBC is to: “Promote and ensure quality of care, safety, commitment, cooperation and collaboration” (DoH, 2001, p. 4).

Muller and Flisher (2005) draw on Brown, Franco, Rafeh & Hatzell (1997) to claim that despite quality assurance processes originating in “first world market driven economies, it has been emphasised that service quality is applicable, and indeed essential, for less resourced, developing countries” (p. 141). This argument is also supported by WHO (2006) and according to Brown, Franco, Rafeh and Hatzell (1997):

> At first glance, high-quality health services may appear to be a luxury beyond the budgetary limits of most LDC [least developed country] health systems. However, improving quality often does not cost, it pays. Attention to quality is essential to the success of primary health care programs, a fact that health managers with restricted budgets cannot afford to ignore. (p. 5)

There is a strong argument that quality assurance is as necessary in developing countries, such as South Africa, as it is necessary in developed countries. In fact a UNAIDS (2000a) document states that in the case of quality CHBC that “the level of funding is not the most important predictor of the quality of care. It is an extraordinary fact that some of the most effective programmes are found in the poorest communities…” (p. 60). However, this is not always the case. For example a study showed that in Botswana, socio-economic and political inequalities play an important role in affecting the quality of CHBC care (Phorano, Nthomang & Ngwenya, 2005, p. 163). Furthermore, in a study on sub-Saharan Africa dealing with CHBC and HIV and AIDS programmes, it was pointed out that CHBC places many challenges on clients and caregivers and their respective communities, which “adversely affect their [caregivers] ability to carry out their activities” (Mohammad & Gikonyo, 2005, Abstract). However, Mohammad and Gikonyo (2005, Abstract) emphasise that CHBC caregivers have the potential to provide “effective and affordable” care to their clients. As this study concerns quality CHBC, and its viability, these sources suggest that attaining quality CHBC is plausible and that despite the obvious challenges can be achieved if suitable structures are in place. Therefore, it is necessary to obtain a deeper understanding of quality CHBC in order to be able to make suggestions concerning its improvement.

The South African government has expressed its support behind the need for quality CHBC and this is shown in the DoH (2001) *National Guideline on Home-Based Care / Community-Based Care* for CHBC which emphasises that quality care and safety are to be both ensured and promoted. In 2007, the DoH compiled a document entitled: *A Policy on Quality in Health Care for South Africa.* The document addresses CHBC directly and indirectly in a number of places with regard to quality health care. First, the document indicates the need to enable patients to care for themselves and this links to the WHO (2006) list of key areas of quality care where the aim is to make care acceptable and patient-centred. The document states: “Empowering individuals with the skills and tools to care for themselves is especially important for individuals with chronic illness or disability. Enabling users to assess their health, practise preventive health care, and self-care, will improve their health and reduce unnecessary health care services and costs” (p. 4). This quote supports the holistic approach that CHBC purports to take and therefore DoH strongly supports the need for quality care in the realm of CHBC and is in line with the benchmarks laid out by both the WHO. Furthermore, the DoH (2007) supports the notion of community participation, which is also linked to the WHO (2006) quality care dimension that covers interpersonal relations. The DoH (2007) states that: “Not only individuals need to be encouraged to participate in health care, but also whole communities. The importance of community action has already been clearly demonstrated in the fight against AIDS” (p. 4). It also states that “Not only is individual patient participation important in improving quality, but also the active involvement of whole communities” (p. 7).

The WHO (2000) states that there are various factors which impact on quality assurance, for instance, “the training and supervision of formal and informal caregivers, information system development, standard-setting and guideline development” (p. 19). In addition, legislation and the capacity of families as caregivers can also play a part in promoting quality, however, the extent and nature of any efforts to improve quality will depend on the resources available (WHO, 2000).

This section discussed the concept of quality CHBC using various sources dealing with quality CHBC. A series of dimensions of quality care from the WHO and from USAID were presented as a guide towards understanding quality CHBC. Furthermore, the DoH is also drawn on to understand quality CHBC in a South African context.

2.16 Conclusion

In conclusion, a definition, description and short history provided an overview of CHBC. Following this, the DoH *National Guideline on Home-Based Care / Community-Based Care* was presented, as well as an overview of HBC and community-based care. This, together with a discussion of CHBC models, provided a fuller picture of the structures in which CHBC occurs. Thereafter was a discussion of CHBC in relation to AIDS and South Africa, AIDS and gender inequality, AIDS and stigma, and AIDS and poverty in order to present a backdrop to CHBC within a local context. After this were discussions of volunteering and willingness to care, which are key reasons for people’s choosing to volunteer. Then, the main role players in CHBC were discussed including supervisors, caregivers, and clients, followed by a presentation of the various caregiver activities because these role players are critical as their ability to operate effectively affects the quality of care. Thereafter, monitoring and evaluation and training were discussed because it is an important process in keeping CHBC organisations and their volunteers accountable. Following this was a discussion of the benefits and disadvantages of CHBC as CHBC is not a perfect system but rather the only system currently available. Finally, quality care was examined in relation to CHBC because clients who would, under other circumstances, be accessing institutional care now rely on community care to provide the same standard of service. The following chapter will be a discussion of the research methodology used for the study.

CHAPTER 3

THEORETICAL FRAMEWORK

3.1 Introduction

Many scholars have used social capital to provide a theoretical framework for examining the impact of people’s networks on their life chances (Field, 2008). This chapter describes how social capital is used as a theoretical framework for this study, which focuses on community home-based care (CHBC) networks consisting of managers, supervisors, volunteer caregivers, clients and their family caregivers. The chapter begins by placing social capital in a historical context. This is followed by a broad description of social capital and then a discussion of the concept of capital. Following this are the definitions of three major contributors to social capital theory: Bourdieu, Coleman and Putnam. Networks are discussed, followed by an explanation of structural and cognitive social capital. After this is a discussion of the concept of social ties. Next is a section on the role of social capital and health, followed by a section on volunteering and a discussion of the relevance of social capital to CHBC.

3.2 Historical context

It has been noted that there are theoretical precursors to social capital in the works of many of the classical social theorists, including Adam Smith, Alexis de Tocqueville, Emile Durkheim and Karl Marx (Ferlander, 2007; Halpern, 2005; Portes, 1998). As a sociologist, for example, Durkheim was interested in people’s social ties and how these ties linked to a wider society (Field, 2008). He observed that, even for the most individualistic of acts (such as suicide), such behaviour could not be understood in isolation from the community with its myriad relationships (Halpern, 2005). The classical social theorists had an interest in social cohesion and the role of community. However, Ferlander (2007) notes that social cohesion and community are not necessarily synonymous with social capital. She says: “Social capital comprises several dimensions, while social cohesion and a sense of community can be regarded as outcomes, as well as sources, of some of them” (Ferlander, 2007, p. 115). This suggests that social capital encompasses a range of aspects in addition to those investigated by the classical social theorists. Perhaps it is this multi-dimensional aspect of social capital that attracts “economists, political scientists, development theorists and sociologists to use this theory to explain why certain communities and societies may be more or less cohesive, economically prosperous, safe, and healthy than others" (Birdsall & Kelly, 2005, p. 13). It was two noteworthy social theorists who placed social capital in a theoretical context, namely Pierre Bourdieu and James Coleman (Szreter & Woolcock, 2004). However, it was Robert Putnam who introduced social capital to a much broader audience, popularising it significantly (Dollery & Wallis, 2003).

3.3 Description

Before looking at the definitions of social capital theory it is useful to look at a more generic description that helps to explain its constituent parts. Generally, individuals belong to distinct social groups that shape their identity, values and priorities and they rely on other people for information, correction and assistance in a spirit of trust, cooperation, and commitment to common objectives (Woolcock, 1998). As Woolcock (1998) says, "Membership in these communities provides (or, importantly, prevents) access to key professional networks, political insiders, and cultural elites; it is also the context in which one gives and receives care, friendship, encouragement, and moral support" (pp. 154-5). The above description by Woolcock is a broad statement regarding the nature of social capital, and based on this description it is clear that social capital is made up of many variables and, as already mentioned, is a complex multi-dimensional concept.

Variations in social capital have been used to explain educational achievement, democracy, levels of crime and poverty (Ferlander, 2007; Herreros, 2004). However, it is also important to bear in mind that social capital may be beneficial to one individual or group of individuals, but at the same time, be useless or even harmful to others (Coleman, 1988).

3.4 Why capital?

Referring to Marx, Lin (2001) states that capital is a part of surplus value and is a product of a process. He goes on to say that capital is also an investment process where surplus value is produced and captured by the dominant class, thus "social capital is an investment in social relations with expected returns" (Lin, 2001, p. 6). Furthermore, the renowned social scientist Pierre Bourdieu (1986) argues the impossibility of understanding the social world without acknowledging the role of "capital in all its forms, and not solely in the one form recognised by economic theory" (p. 242). Bourdieu identifies various kinds of capital including economic, cultural and social capital. On the other hand, Serageldin (1996), referred to by Uphoff (2000), lists four categories of capital: physical (human made), natural, human and social.

Portes and Landolt (2000) show how Bourdieu emphasised the need for trade between money capital, cultural capital and social capital to allow for their development. Indeed, an important aspect of capital is that it is transferable and this transferability is achieved through its reduction to cash. Social capital, according to Field (2008), is not readily translated into cash terms, but it does have a high degree of transferability or fungibility as human capital. Human capital is the knowledge and skills accumulated by an individual that may increase his or her potential to improve his or her job prospects resulting in an increase in personal income. This aspect of social capital is particularly relevant to CHBC, especially regarding the knowledge and skills acquisition of volunteer home-based caregivers. Furthermore, they are also able to transfer their knowledge and skills to both their clients and their clients' primary caregivers.

3.5 Definitions of social capital

Social capital definitions generally contain two main aspects: one structural and the other cognitive (Ferlander, 2007; Uphoff, 2000). Most definitions revolve around three elements: social networks, norms of reciprocity and trust (Ferlander, 2007). This section will look at the definitions of three prominent social scientists, namely, Pierre Bourdieu, James Coleman and Robert Putnam.

3.5.1 Social capital as a "construction of sociability"

Bourdieu defined social capital as an "aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalised relationships of mutual acquaintance and recognition" (Bourdieu, 1986, p. 248). As one of the first social theorists to define social capital, it is interesting to note the emphasis on the concept of networks and specifically a "durable network." This links to the concept of sustainability, and regarding non-profit organisations (NPOs) that run CHBC programmes this is particularly relevant, as they are continually struggling to survive.

Portes (1998) comments on Bourdieu’s influence on social capital: “His treatment of the concept is instrumental, focusing on the benefits accruing to individuals by virtue of participation in groups and on the deliberate construction of sociability for the purpose of creating this resource” (p. 3). In the context of this study, CHBC organisations usually develop organically with a small group of volunteers operating informally, but eventually resulting in the volunteers arranging themselves into a more formal group, such as a community-based organisation (CBO) (Symes, 2006). The caregivers need the support to keep going in the work they do, so there is a “deliberate construction of sociability” in order to create the “resource” of support. The possible “benefits” acquired by the caregivers are emotional support, spiritual support, advice and material resources.

Bourdieu was interested in how social capital was used by elite groups to their advantage and how social capital created inequality to the benefit of a few (Field, 2008). According to Field (2008), this interest in inequality is connected to Bourdieu’s early interest in Marxism, although by the time he started writing about social capital he had long since abandoned explicit Marxist thought. Bourdieu was of the opinion that social capital was limited to a few elite groups and therefore it was only beneficial to these groups (Lin, 1999). This view is perhaps not applicable to the South African situation where large sections of the population are underprivileged. Are they unable to create social capital or rather is there no inherent social capital in their communities? Does one need to be in a particular education bracket, or class or economic group to engage in activities that constitute social capital? This study would argue that this is not always the case.

3.5.2 Social capital as functionality

Coleman (1988) states that social capital is defined by its function:

> It is not a single entity, but a variety of different entities, with two elements in common: they all consist of some aspect of social structures, and they facilitate certain actions of actors – whether persons or corporate actors – within the structure. (p. 98)

Coleman’s view of social capital was strongly influenced by rational choice theory, which regards all behaviour as the result of individuals’ pursuing their own interests; social interaction is therefore viewed as a form of exchange (Field, 2008). Greshoff, Huinink and Schimank (2011) state that Coleman argued that: “collective social phenomena can roughly be divided into ‘merely aggregated individual behavior’ and ‘interdependence of individuals’ actions’” (p. 4). Hence, rational choice theory places a strong emphasis on individuals and less on structures, and tends to ignore culture (norms and shared meaning), and affect (altruism, love and friendship) (Field, 2008).

According to Field (2008), rational choice theory assumes that participation in collective behaviour represents a deviation from the norm, which consists of individuals pursuing their own private interests, if necessary at the expense of others. Coleman believed that social capital arises not because actors make a calculating choice to invest in it, but as “a by-product of activities engaged in for other purposes” (Coleman, 1994, p. 312). Hence, Coleman’s understanding of social capital does not place a great emphasis on altruism, which is a concept that is very relevant in a study of volunteerism and CHBC. In South Africa, one certainly cannot ignore the concept of *ubuntu* which has a very strong focus on the collective as opposed to individualism. However, Coleman does accept the value of connections for all actors, individual and collective, privileged and disadvantaged (Field, 2008).

3.5.3 Social capital as social networks and norms

Putnam’s initial definition of social capital was as follows: “Social capital … refers to features of social organisation, such as trust, norms and networks, that can improve the efficiency of society by facilitating coordinated actions” (Putnam, 1993, p. 167). So his focus in this definition is on “trust, norms and networks.” In *Bowling Alone,* Putnam (2000) refines his understanding of social capital theory, stating that: “...the core idea of social capital theory is that social networks have value...social contacts affect the productivity of individuals and groups” (pp. 18-19). He defines the term itself as referring: “to connections among individuals – social networks and the norms of reciprocity and trustworthiness that arise from them” (Putnam, 2000, p. 19). So in this definition he reduced the meaning of social capital to social networks and norms, or structural and cognitive elements. In CHBC, these two elements are very important, because the success of a CHBC programme is reliant on a well-structured organisation. Furthermore, its success also depends on the presence of volunteers who adhere to the norms and values that inspire them to do care work. The following section deals with these two elements of social capital.

3.6 Structural and cognitive social capital

This section presents two important aspects of social capital namely its structural and cognitive elements. Structural elements refer to social organisations while cognitive elements refer to norms of reciprocity and trust.

3.6.1 Structural social capital

The social network can be seen as the structural aspect of social capital (Ferlander, 2007). However, Uphoff (2000) also adds various forms of social organisation to structural social capital, namely: 1) roles, 2) rules, 3) precedents, and 4) procedures. These factors all contribute to cooperation, and to mutually beneficial collective action, which is the stream of benefits that results from social capital (Uphoff, 2000). Islam, Merlo, Kawachi, Lindström, and Gerdtham (2006) refer to structural social capital as externally observable aspects of social organisation, such as density of social networks, or patterns of civil engagement.

3.6.2 Cognitive social capital

Ferlander (2007) states that norms of reciprocity and trust are what constitute cognitive social capital, to which Uphoff (2000) adds, values, attitudes and beliefs. He also emphasises the importance of culture and ideology. “Norms of reciprocity” have been defined as various forms of exchange of social support (Blanchard & Horan, 1998, as cited in Ferlander, 2007). Social support can be divided into emotional, instrumental and informational support and social companionship (Cohen & Wills, 1985, as cited in Ferlander, 2007). Support of this nature is particularly relevant to the concept of CHBC. Ferlander (2007) explains emotional support to be the provision of empathy, trust and caring; instrumental support refers to practical help, for example, in relation to money or labour; and informational support is seen as the provision of advice and information leading to a solution to problems. Companionship involves spending social time with others in the form of leisure time. According to Upfhoff (2000), ideas in cognitive social capital “predispose people” (p. 218) toward mutually beneficial collective action, because to a large degree, once ideas are shared with others, opportunities for cooperation are more likely to occur. Norms, values, attitudes and beliefs create expectations about how people should act and therefore, how they will act; hence, subjective impetuses have objective consequences (Uphoff, 2000). Cognitive social capital does not occur in isolation, but occurs between people in various kinds of networks.

3.7 Networks

Uphoff (2000) describes a network as a pattern of social exchange and interaction that persists over time, which is a manifestation of social capital (both informal and formal). Social networks are the means through which the resource of social capital is accessed (Ferlander, 2007) and these social networks have a value (Putnam, 2000) and can be regarded as assets (Lin, 2001). Field (2008) states that “networks provide a basis for social cohesion because they enable people to cooperate with one another – and not just with people they know directly – for mutual advantage” (p. 14). Networks are held together by mutual expectations of benefit, but they are sustained by expectations or norms of reciprocity (Uphoff, 2000).

Social capital can be viewed as either benefiting or belonging to individuals or a group or both individuals and a group (Ferlander, 2007). Furthermore, one can look at social capital at a micro-level (social network of individuals), at a meso-level (community or neighbourhood) and at a macro-level (national) (Halpern, 2005; Islam et al., 2006). When networks within the social capital concept are viewed with these different levels in mind, it becomes clear that it is a complex concept and from an empirical perspective it requires a multilevel approach. However, at present the majority of social capital empirical studies are single level studies (Islam et al., 2006).

3.8 Social ties

Social networks have been conceptually distinguished by the direction of their ties and their levels of formality, strength and diversity, yielding horizontal, vertical, formal and informal networks (Ferlander, 2007). The horizontal can be further classified as bonding, bridging, strong or weak, while the vertical are also referred to as linking.

3.8.1 Horizontal ties

Horizontal ties exist between individuals or groups of equals or near-equals (Islam et al., 2006). They foster strong norms of reciprocity, ease of communication and the flow of information about the trustworthiness of others (Putnam, 1993). Horizontal ties can be further divided into bonding and bridging ties.

3.8.1.1 Bonding ties

Woolcock (2001) states that bonding social capital indicates ties between like people in similar situations, such as immediate family, close friends and neighbours. For Putnam, bonding (or "exclusive") social capital is inward-looking and binds people from a similar sociological niche; it tends to "reinforce exclusive identities and homogenous groups" (Putnam, 2000, p. 22).

3.8.1.2 Bridging ties

However, bridging social capital encompasses more distant ties of like persons, such as loose friendships and workmates (Woolcock, 2001). Putnam (2000) notes that bridging (or "inclusive") social capital tends to generate broader identities and wider reciprocity rather than reinforcing a narrow grouping.

3.8.1.3 Strong ties and weak ties

Two other types of social capital are strong ties and weak ties, which are often regarded as being the same as bonding and bridging ties. However, Ferlander (2007) states that bonding ties refer to people who are "similar to oneself," but strong ties refer to people who are "emotionally close to oneself" (p. 119). On the other hand, bridging ties refer to people who are different from oneself, while weak ties refer to people who are emotionally distant from oneself (Ferlander, 2007).

3.8.2 Vertical ties

Vertical ties, which were first introduced by Woolcock (1998), are also referred to as linking social capital. Such ties stem from hierarchical or unequal relations due to differences in power or resource bases and status (Islam et al., 2006). Vertical ties reach out to unlike people in dissimilar situations and enable members to leverage resources, ideas and information from contacts outside of their own social milieu (Field, 2008; Woolcock, 2001).

3.8.3 Formal and informal ties

Formal ties are characterised by contacts within voluntary associations, and also between citizens and civil servants, but they cannot be considered to be synonymous with bridging or vertical ties (Ferlander, 2007). For example, one may consider one's associates at a voluntary organisation to be friends, which would make the relationship an informal one, although the relationship could be viewed on two levels, namely work-based and friendship-based.

Informal ties take the form of contacts among friends, family, neighbours and colleagues (Ferlander, 2007). Informal ties consist largely of what has already been referred to as bonding ties. However, Islam et al. (2006) note that "shared trust, norms and values arise from informal forms of organizations based on social network and association" (p. 5).

3.9 Social capital and health

Putnam (2000) states that "of all the domains in which I have traced the consequences of social capital, in none is the importance of social connectedness so well established as in the case of health and well-being" (p. 326). The idea that social cohesion and health are related is at least a century old with Durkheim showing that suicide rates were higher in populations with low levels of social integration, but lower in closely knit communities (Field, 2008). Furthermore, there are many empirical studies that demonstrate that health and social capital are closely related as Islam et al. (2006) show. Halpern (2005) concurs, stating that there have been many cross-sectional studies showing the strong connection between "the size and quality of people's social networks and their health, with people who are less socially isolated and more involved in social and civic activities tending to have better health"(p. 75). The influence of social capital on health is more evident in unequal societies (where there is an unequal distribution of resources), such as in the United States of America (USA), than in Scandinavian countries (Borges, Campos, Vargas, Ferreira & Kawachi, 2010), with their established social welfare systems. Furthermore, social capital also plays an important role in people who are already ill, because it has been shown that people who have suffered strokes or heart attacks are more likely to survive if they have high levels of emotional support (Ferlander, 2007).

There is no doubt that social capital and the health of individuals are closely related. However, it is still a very difficult concept to measure owing to its complex nature (Campbell, Williams & Gilgen, 2002). A number of variables need to be taken into consideration when measuring social capital in relation to health. First, most surveys for mental health are self-rated surveys whereby the participants indicate their levels of health on the questionnaire (Halpern, 2005; Islam et al. 2006). However, in the case of participants suffering from depression, their answers may be more negative, because of their general negative perception of life (Halpern, 2005). This will skew the answers, resulting in respondent bias. Second, causal factors are often unclear; for example, do people feel isolated because of their poor health, whereby their illness keeps visitors away, or is it their isolation that has led to their poor health (Halpern, 2005)?

Social networks can also influence negative habits and behaviour, especially where negative peer pressure is present. Berkman, Glass, Brissette and Seeman (2000, p. 850) state that unhealthy behaviours such as immoderate tobacco and alcohol consumption, poor dietary patterns, dangerous sexual practices, and illicit drug use can be a negative consequence from social networks. This is especially relevant to the situation in a high HIV prevalent society. Owing to peer pressure, there is a tendency for people to follow the group and the norms and values of the group even if they are inclined towards high risk or unhealthy behaviour patterns (Ferlander, 2007). In the context of HIV and AIDS, Carey, Scott-Sheldon, Carey, Cain, Mlobeli, Vermaak, Mthembu, Simbayi & Kalichman (2011) refer to a number of sources to support their argument that social norms appear to affect behaviour, stating: "norms predict behavioral intentions and behavior in part because they signal what will be accepted/approved by the group" (p. 32).

3.10 Volunteerism

According to Hall (1999), membership in voluntary associations is at the core of the conventional definition of social capital, and those voluntary associations may be dedicated to a variety of purposes ranging from the recreational or social to the religious or political. Hall (1999) states that changes in the membership of these kinds of voluntary associations provide one of the best indicators of trends in social capital. Hence, to Putnam (1993), a society with high levels of voluntary activity is a society with high levels of social capital. He placed an emphasis on voluntary associations, arguing that they bring “equivalent status and power” (Putnam, 1993, p. 173), which then promote cooperation and result in the creation and continuance of a civil society and social capital (Ferlander, 2007). One of the most commonly used indicators for measuring different societies’ social capital is indeed membership of voluntary associations (Islam et al., 2006). Harper and Kelly (2003, p. 8) note that “voluntary work is an important indicator of people’s willingness to undertake activity that benefits others and the wider community.”

3.11 Social capital and community home-based care

Social capital was chosen for this study to act as a lens through which to view CHBC. The primary reason why it was chosen was that social capital places a strong emphasis on networks. Indeed, two of the above mentioned definitions of social capital refer to the presence of networks of social relations.

CHBC volunteers do not operate in isolation and are often associated with formal or informal groups of people who have a common goal, to care for the sick (DoH, 2001; Tshabalala, 2008). Each group of caregivers can be referred to as a network and in each community there are many networks, often operating in isolation from other networks, but of course not in isolation from the community. When the concepts of social capital are inserted into the reality of CHBC then the usefulness of the theory becomes apparent.

Volunteer caregivers are usually members of the communities in which they work (Akintola, 2010; Van Dyk, 2008; Symes, 2006). They form a network of social relations (as neighbours or as residents) that occurs at the meso-level of the community or neighbourhood. The volunteer caregivers have received a certain amount of training and knowledge, and because they are associated or affiliated with NPOs or CBOs or faith-based organisations (FBOs), they also belong to a separate group (or network) within the larger community network.

Volunteer caregivers will have strong ties with certain members of their community, but not all the members. They would tend to have all the characteristics of the community members with whom they live, such as language, race and culture. Therefore, the caregivers and their clients have bonding ties between them (bonding ties being ties between like people in similar situations), but they will also consist of strong and weak ties (emotionally close and emotionally weak ties respectively).

However, at the micro-level, especially between the volunteer caregivers and their clients there are bridging ties, which are loose ties. Domínguez and Arford (2010) note that bridging ties exist between socially dissimilar people. In the context of CHBC the caregivers are dissimilar to their clients from the point of view that they receive CHBC training, knowledge and support from their respective CHBC organisations. Hence, these bridging ties ensure that there is an exchange of social support between the clients being cared for and their caregivers. Social support is emotional, instrumental, and informational support and social companionship. This is exactly the kind of support that volunteer caregivers are expected to provide to their clients. Clients who have access to a network of volunteer caregivers have higher levels of social capital than those clients who do not have access to them.

There are also bonding ties between the volunteer caregivers themselves. They too need social support in their work as caregivers and it is possible that they are able to receive such support from their fellow caregivers. It could be argued that they hold the same norms, values, attitudes and beliefs based on the fact that they all have a common goal, namely to care for sick people. This is itself a uniting factor. Uphoff (2000) states that "norms, values, attitudes, and beliefs by creating expectations about how people *should* act . . . create expectations about how people *will* act" (p. 219, author's italics). The concept of *Ubuntu* is a philosophy that even if it is not as dominant as it was in the past (owing primarily to the influence of modern popular Western culture), will still play an important role in governing the behaviour of many volunteer caregivers. One generalised “expectation” of *Ubuntu* is that the community is one’s extended family and that caring for one’s family, especially for children, is the responsibility of all community members. This is demonstrated by the many grandparents who have welcomed orphans into their homes throughout Africa due to the HIV and AIDS epidemic (Tamasane & Head, 2010; Hlabyago & Ogunbanjo, 2009).

At the meso-level of communities, it can happen that there is an exchange of ideas and information between different CHBC organisations. An organisation may find a source for cheap maize meal and could share that information with another organisation. This would be an example of horizontal ties existing between groups of equals or near-equals (Islam et al., 2006), namely two CHBC organisations. Such horizontal ties are sustained by “expectations (that is, by norms) of reciprocity” (Uphoff, 2000, p. 219).

As mentioned, linking ties originate from hierarchical or unequal relations due to differences in power or resource bases and statuses (Islam et al., 2006). There are a number of examples of linking ties that occur in the CHBC situation. This could be in the form of outside training agencies that come into the community to teach the volunteer caregivers CHBC skills. It could be in the form of retired professional nurses who guide the volunteers and clients with their knowledge and skills that they have acquired from years of working in health care institutions. It could also be in the form of non-governmental organisation (NGOs) assisting CHBC organisations with writing proposals to access external funding.

3.12 Conclusion

Community networks and social capital play an important role in CHBC. The many varieties of ties that exist in the communities have the potential to sustain CHBC and to also help to extend the coverage of care being provided. It is possible that communities with high levels of social capital are more likely to have better quality CHBC. Volunteerism, an important aspect of social capital, is critical to achieving some kind of success in CHBC. However, the challenge is how to maintain high levels of social capital, including its voluntary aspect, especially after it is transferred from an informal form (such as a church initiative) to a more formal professional form (such as a registered NPO). The following chapter examines the concept of CHBC in more detail by looking at its history, its objectives and its structural and social aspects.

CHAPTER 4
METHODOLOGY

4.1 Introduction

Chapter 4 begins with the research design, which includes a discussion of the meta-theory, followed by a presentation of the qualitative and quantitative designs of the study. After the research design is an explanation of the research procedure. The procedure demonstrates the manner in which the research took place, beginning with the development of the questionnaires followed by an explanation of their translation and then a discussion of the piloting of the questionnaires. Following this is a brief description of interviewer-fieldworkers who conducted the interviews. The process of selecting the community home-based care (CHBC) programmes is then explained followed by a description of the study participants and the sampling process. The process of data collection and how the analysis took place is then presented. Finally, the trustworthiness of the study is presented followed by a discussion of the ethical considerations.

4.2 Research design

This section discusses the research design of the study, which includes the methodology. The philosophical world view that guided the study is presented followed by the "strategy of enquiry". Then the particular research approach is discussed, and in this study, both a quantitative and a qualitative approach were utilised.

As mentioned in Chapter 2, the theoretical framework for this study is social capital theory. However, the research meta-theory or "strategy of enquiry" (Creswell, 2009) used in this study is phenomenology. Edmund Husserl is often credited with being the father of phenomenology although the concept can be traced to Kant (Titus, Smith & Nolan, 1979). Thereafter, it was Alfred Schutz who introduced the concept into sociology (Ritzer, 1988). Husserl believed that in order to arrive at certainty, anything outside immediate experience must be ignored, thus the external world is reduced to the contents of personal consciousness (Groenewald, 2004). Hence, phenomenology is described as "the study of lived, human phenomena within the everyday social contexts in which the phenomena occur from the perspective of those who experience them"

(Titchen & Hobson, 2006, p. 121). Delport and Fouché (2005) state that phenomenology attempts to understand people's perceptions, perspectives and understanding of a particular situation. Indeed, this is the purpose of this study as it aims to understand CHBC and specifically quality CHBC through the perceptions, perspectives and understanding of all the role players who are engaged in the process of CHBC. The research approach that lends itself to acquiring knowledge through the phenomenological strategy of enquiry is the qualitative research approach.

The purpose of a phenomenological study is to describe the meaning of the experiences of a phenomenon, topic or concept for various individuals. This study includes descriptions of the experiences of volunteer caregivers, clients and supervisors with regard to their involvement with CHBC and as they relate to quality care. Moustakas (1994) says the researcher reduces the experiences to a central meaning or the essence of the experience. Hence, the product of the research is a description of the essence of the experience being studied (Fouché, 2005). The essence of this study is the lived experiences of all the role players who participate in CHBC services as they relate to the concept of quality care.

In addition to the qualitative approach, owing to the use of a series of questionnaires containing a mixture of closed and open-ended questions, the quantitative approach was used to a lesser degree. The aim of the closed-ended questions in the questionnaires was to collect quantitative or numeric data from the participants with a view to describing the attitudes, trends or opinions of a population, through a sample of that population. The purpose of the closed-ended (quantitative) questions was to complement the qualitative data in order to gain a broader perspective of the issues surrounding quality CHBC.

The following section deals with the sources that were used to stimulate ideas for both the quantitative and qualitative questions in the three questionnaires.

4.3 Procedure

Three questionnaires were developed to obtain information from the caregivers as well as the clients and supervisors. Essentially, the caregivers' and clients' questionnaires were designed with the view to their being used as structured interview schedules while the supervisor questionnaire was to be self-administered as it was assumed that the supervisors would have higher levels of literacy owing to them largely being retired nurses.

The aim of the questionnaires was to provide information on volunteer caregivers, what constitutes quality care and to what extent participants were providing quality care. Chapter 3 discussed benchmarks of quality care based on guidelines by the World Health Organisation (WHO) (2006) which noted that quality care should be effective, efficient, accessible, acceptable/patient-centred, equitable and safe. Some of these benchmarks overlapped with those of the United States Agency for International Development (USAID) (n.d.), which also listed the following requirements for quality care: technical competence, interpersonal relations, continuity and amenities. Furthermore, Chapter 3 also referred to the importance of standardisation in providing quality care. The structure of these questionnaires enabled the researcher to determine to what extent these benchmarks of quality care were being met as well as enabling the researcher to determine what quality means within these parameters.

4.3.1 Questionnaires

The three questionnaires were developed from a variety of sources of CHBC literature. At the beginning of this study, a number of sources were used to inform the development of the three questionnaires. Key documents were the WHO documents, South African Department of Health (DoH) documents, journal articles, and dissertations and theses. The above documents, because they provide directives advising how CHBC should be undertaken, were useful in helping to stimulate ideas for questions for the questionnaires, both quantitative and qualitative.

The WHO document that proved useful in this study was entitled *Community Home-Based Care in Resource-Limited Settings: A Framework for Action* (2002). The sections on the ill person, family members and CHBC members (WHO, 2002) were also informative, as they presented a set of indicators concerning quality care in a CHBC setting. The indicators covered the issue of “access” and whether clients had access to a range of health care-related services.

The South African DoH (2001) *National Guideline on Home-Based Care / Community-Based Care* was also an important background document for the questionnaires. For example, the section entitled “Principles of home-based care and community-based care” presents issues such as “holistic” care, “person-centred” care and “comprehensive” care (DoH, 2001, p. 4) as these are important aspects of CHBC. This stimulated the development of questions that sought to find answers that could determine if the care received by the clients was indeed holistic, person-centred and comprehensive. Another section that was valuable was the “Challenges of home-based care” (DoH, 2001, p. 10). These challenges applied to both the caregivers and the clients and covered issues such as “emotional and physical strain and stress experienced by caregivers” or “fear or mistrust of the primary caregivers.” These sections were valuable in the developing questions around trust, an important aspect of social capital.

Another key document was the Kenyan *National Home-Based Care Programme and Service Guidelines* (Kenyan Ministry of Health, 2002). Again, this was an essential document for placing CHBC in context with all its strengths and weaknesses. The document has three sections: “The Rationale for home-based care,” “Programme guidelines” and “Service guidelines.”

A comprehensive book which provided essential information was *Home-Based HIV/AIDS Care* by Uys and Cameron (2003). The chapter entitled “Training community caregivers for a home-based care programme” by Cameron was insightful regarding the activities and skills needed by volunteer caregivers. Furthermore, the chapter by Knott (2003) entitled *Counselling in the context of HIV/AIDS* was an informative guide with regard to questions concerning the counselling of clients. Marston’s (2003) chapter, *Doing a home visit* was also helpful in setting the context of home-based care (HBC) visits.

Furthermore, a number of dissertations concerning CHBC contained interview schedules regarding various aspects of volunteer caregivers and clients. A dissertation by Soal (1994) entitled *An Evaluation of a Home-Care Project for People with HIV and AIDS* was an effective resource for this study. This dissertation was an evaluation of a Red Cross HBC pilot programme in the Western Cape, and a number of questions from this interview schedule were helpful in the development of the interview schedules in this study as they were looking for specific aspects regarding HBC that were relevant to the current study. A dissertation by Sapepa (1998) was also used as a resource and was called *Description of Home Based Care (HBC) for People Living with AIDS (PWA) in Region E, of the Eastern Cape* (Sapepa, 1998). Van Wyk's (2002) dissertation, *Burnout in Home-Based Carers Nursing People Living with HIV/AIDS* suggested ideas regarding the development of questions concerning the burnout of caregivers. Section B of her interview schedule had a semantic differential scale that was shortened and adapted for Section J of the caregiver questionnaire. The dissertation entitled *An Assessment of the Psychological Support Given and Received by Home-Based Caregivers Working in the North West Province* by McKenzie (2006) was also a work used to develop questions on emotional needs of caregivers. Three of these studies were in the field of psychology, and one was in the field of nursing. All these dissertations were useful, because they contained many questions that the researcher was able to use or adapt as items in the interview schedules.

In addition, Buch (2002) of the University of Pretoria developed an evaluation instrument entitled *Participatory Rapid Appraisal Tool for the Evaluation of AIDS Home-based Care Programmes*. This instrument was also valuable as it contained many relevant concepts for this study. Not all the questions were specific, although they were semi-structured, allowing the interviewer freedom to ask her own questions to elicit the required information.

In 1993, in the United States of America (USA), Ferrari et al. conducted an evaluation in order to examine the experiences of AIDS caregivers with regard to job satisfaction and stress (Ferrari, McCown & Pantano, 1993). They compiled an AIDS Caregiver Scale where satisfaction items and stress items were listed, and these were found to be useful and were adapted and used in the questionnaires.

Another helpful study was carried out by Abell (2001), a study into the willingness of caregivers to care for persons living with HIV or AIDS (PLHAs). Willingness to care can be defined as a caregiver's attitude toward providing emotional, physical, and instrumental support to a terminally ill person, especially people with HIV and AIDS (McDonell, Abell & Miller, 1991). According to Abell (2001), there are three major domains regarding a caregiver's willingness to care: 1) emotional support: the caregiver may be called on to offer comfort when the ill person is in distress, listen to expressions of anger or grief, or accept their choice of friends or companions. 2) Instrumental support: involving meal preparation, cleaning the house, or providing transportation to medical appointments. 3) Physical or nursing support: including changing soiled bed linen, bathing or assisting the sick person in and out of bed. Another aspect of care, as highlighted by Abell (2001), was the ability of caregivers to care, or rather, to do the tasks they believed they could perform if necessary. Elements of all four of these aspects of care were adapted and used in the questionnaires.

Two other studies were helpful regarding the questionnaire: One was Wardlaw's study investigating how to sustain informal caregivers in their work as carergivers of PLHAs (Wardlaw, 1994). The other was a needs assessment of caregivers of PLHAs by Theis, Cohen, Forrest and Zelewsky (1997) that provided useful information on caregivers' needs.

4.3.2 Translations

All the questionnaires were translated from English into isiXhosa and Afrikaans as together with English, these languages are the official languages of the Eastern Cape. Two professional translators undertook the translations (see Appendix A). It was decided to include all three languages on each questionnaire. This had certain advantages: 1) only one set of questionnaires needed to be printed for the supervisors, caregivers and clients; 2) paper was saved and costs kept down; 3) there was no possibility of bringing questionnaires with the wrong language on the field trip; 4) there was no possibility of running out of questionnaires of a particular language and 5) the interviewers could ask the questions in all three languages if the caregiver or client being interviewed was able to understand the question more easily in another language. For instance, technical medical terms are not always used in everyday isiXhosa; therefore, the English versions may sometimes be more familiar to the interviewee. The inclusion of all three languages on the questionnaire helped to discourage the interviewers from providing their own translations and thereby remaining as true to the original meaning of the question as possible.

4.3.3 Piloting the questionnaires

A pilot study of the questionnaires was undertaken before the interviews took place in order to test various aspects of the questionnaires with the assistance of retired nurses. A pilot study is used to "detect possible flaws in the measurement procedures" and to "identify unclear or ambiguously formulated items" (Welman, Kruger & Mitchell, p. 148). The Afrikaans, isiXhosa and English versions of caregiver and client questionnaires were piloted. The retired nurses were working as supervisors at a CHBC programme and were also able to complete a supervisor self-administered questionnaire for the pilot. Altogether, three caregiver and three client questionnaires were piloted. A limited number of changes were made to the questionnaires based on the feedback from the pilot.

The researcher was also able to note the length of time taken to complete the questionnaires. This was, on average, one hour for both questionnaires. However, it was felt the questionnaire could not be shortened, because an in-depth response was sought after.

4.3.4 Interviewers

After the pilot questionnaires were tested, retired nurses were enlisted to assist with the interview process. They were charged with interviewing both the volunteer caregivers and the clients. The retired nurses had a number of attributes that made them suitable for interviewing volunteer caregivers and clients. Such attributes were especially relevant with clients suffering from a variety of conditions including AIDS. First, the retired nurses were familiar with the physical conditions, often poverty stricken, where the interviews took place. Second, they were used to dealing with very ill patients, so they would not be overly shocked when confronted with clients who were affected by unusual or severe ailments. Third, their nursing background meant that they had a certain amount of experience with counselling, and all four had completed basic counselling training, thus they were equipped to respond to sensitive situations. Fourth, all four were fluent in isiXhosa and English, and two were also fluent in Afrikaans, thereby overcoming potential language barriers. And fifth, all four were currently involved in CHBC as supervisors, thus making them familiar with how CHBC operates.

The interviewers used the questionnaires as interview schedules to conduct the interviews, and they completed them on behalf of the participants during the interview. The reason for this was that not all caregivers or clients have equal literacy levels or are proficient in writing, especially regarding the completion of questionnaires. Therefore, in order to increase the response rate and minimize inconvenience to the interviewees, it was felt that using the interviewers to fill in answers on behalf of the interviewees would be the most effective (Appleton, 1995).

The interviews with the volunteer caregivers mostly took place at central points, such as the offices of non-profit organisations (NPOs) that run the CHBC programmes as this was most convenient for both interviewers and interviewees. However, the majority of the clients were interviewed at their homes. This prevented their being inconvenienced and disrupted by having to leave their homes. Furthermore, bedridden patients cannot be expected to travel to an interview.

4.3.5 Identifying CHBC programmes in the Nelson Mandela Bay Municipality

The Nelson Mandela Bay Municipality (NMBM) AIDS Training, Information and Counselling Centre (ATICC) provided a list of HIV and AIDS-related organisations, as at the beginning of the study, there was no database of CHBC programmes, only a general list of all AIDS-related organisations. This list was found to be inconclusive and dated. A reason for this is that NPOs that run CHBC programmes are generally community initiatives with a large volunteer element. Such NPOs often have short life spans and appear quite suddenly with little or no record of their existence. They are generally formed as a response to a particular need in the community, by a certain individual or group of individuals hoping to fulfil that need (Symes, 2006). A short list of CHBC organisations was extracted from the ATICC database.

A second source of information was a Port Elizabeth non-governmental organisation (NGO) that provides mentoring and support to community-based organisations (CBOs). It provided a list of organisations that it was mentoring. However, not all of these were in Port Elizabeth, and not all of these were specifically aimed at CHBC. However, a list of relevant organisations from this database was combined with the list from ATICC. These lists contained the contact details of the organisations and the researcher was able to make general telephonic enquiries about the size and age of each organisation. However, some of the organisations were no longer in existence, or there was no way of contacting them, because the telephone number was no longer in use. However, once the interview process with the managers of the organisations began, it was possible to use snowball sampling to determine the existence of other CHBC organisations. Often the managers were able to introduce the researcher to managers of other CHBC organisations, resulting in easier access to the organisation. Hence, the main procedure for identifying CHBC programmes was through selected information gathered from people who work in the field. Therefore, non-probability purposive sampling was used to determine the NPO sample. Initially it resulted in the identification of 18 registered NPOs which operated CHBC programmes in the NMBM. However, in the end thirteen organisations participated in the study, because some of the organisations, focused exclusively on caring for orphans and vulnerable children (OVCs) and this study aimed to analyse CHBC for adults. Furthermore, a number of CHBC programme managers were reluctant to participate for various reasons, such as difficulties with staff members and volunteers.

Table 4.1 Information for each CHBC organisation

No.	Organisation	Start	NPO	Age	Volunteers	Nurses	Clients	OVCs
1	Agency 1	2003	2006	7	34	0	118	300
2	Agency 2	2003	2004	7	13	2	60	29
3	Agency 3	2002	2002	8	13	3	42	40
4	Agency 4	2000	2002	10	3	1	40	340
5	Agency 5	1989	N/A	21	9	1	450	32
6	Agency 6	2002	2004	8	10	1	71	264
7	Agency 7	1994	2009	16	102	9	828	N/A
8	Agency 8	1999	1999	11	8	2	40	85
9	Agency 9	2003	2005	7	15	1	185	131
10	Agency 10	2004	2005	6	10	0	140	30
11	Agency 11	1993	2000	17	10	0	60	N/A
12	Agency 12	2004	2005	6	320	1	1920	N/A
13	Agency 13	2004	2006	6	5	2	35	N/A

The sizes of the CHBC programmes ranged from as little as three volunteer caregivers to as many as 34 volunteer caregivers. However, two of the CHBC programmes are known to be of an exceptionally large size with volunteer caregivers and clients covering all parts of the NMBM. For this reason, purposive sampling was used to ensure that these particular CHBC programmes were adequately represented.

Purposive sampling is “a type of nonprobability sampling in which the units to be observed are selected on the basis of the researcher’s judgement about which ones would be the most useful or representative” (Babbie, 2007). The largest organisation claims to have 1920 clients (it does not have accurate records), with 320 volunteers, and the other organisation has 828 clients with 102 volunteers.

4.3.6 Participants

The participants who took part in the study included CHBC programme managers, supervisors, volunteer caregivers, clients, key informants and focus group participants. Table 4.2 indicates the number of participants who took part in the study.

Table 4.2 Number of participants

Participants	**Number**
Managers	13
Supervisors	16
Caregivers	32
Clients	32
Key informants	4
Participants from 2 focus groups	8
TOTAL	**105**

4.3.6.1 Managers

The manager population consisted of managers who run CHBC programmes in the NMBM. The manager sample was a non-probability purposive sample taken from the NPO CHBC programme sample. Altogether, the managers of 18 NPO CHBC programmes were interviewed to determine if their organisations were suitable for the study. The CHBC programme managers were, in most cases, the founders or co-founders of each of the NPO organisations in the study and therefore involved in founding the care programmes themselves. The word “manager” is a generic term, as in some cases the person in charge was referred to as a director, a chairperson, a supervisor or a co-ordinator. The word “manager” therefore covers all of these terms. The managers varied in profession from retired nursing sisters to teachers, and in some cases they had no qualifications.

4.3.6.2 Supervisors

The supervisor population consisted of all the supervisors who supervise the volunteer caregivers in the CHBC programmes. The supervisor sample was selected from this population, which is also the sampling frame and the unit of analysis for this sample frame was the supervisor. A minimum of one supervisor was selected from each NPO CHBC programme. It was initially proposed to use systematic random sampling to select the supervisors from each CHBC programme. However, most of the organisations in the NPO sample only have one supervisor each. In the two larger organisations it was decided to ask more than one supervisor per organisation to complete the questionnaire in order to obtain a more representative sample. Sixteen supervisors from twelve of the thirteen NPOs in this study completed the supervisor questionnaires. One supervisor proved difficult to locate, and in the end it was decided to settle for 16 completed supervisor questionnaires.

There was a need to obtain the views of the supervisors of the volunteer caregivers because the supervisor’s role is to guide and support the volunteer caregivers in their care work. Many of the supervisors would have a professional care background, being nurses or retired nurses; therefore their perspective of CHBC would be valuable. The supervisors’ understanding of the needs and difficulties of the volunteer caregivers is an important aspect of understanding the volunteers and the care they provide.

4.3.6.3 Volunteer caregivers

The volunteer caregiver population consisted of volunteer caregivers in the NMBM. The volunteer caregiver sample frame consisted of all volunteer caregivers who are officially attached to CHBC programmes and the unit of analysis for this sampling frame was the volunteer caregiver.

The following scenario occurred on a number of occasions: The researcher, after obtaining a list of caregiver names from the manager, made a random selection of caregivers. Although two volunteer caregivers were ultimately selected from each CHBC programme, the researcher initially submitted four names in advance (in case one or two of the caregivers were unavailable), either in person, by telephone or by SMS to the manager. However, the manager did not always select the people on the list, but replaced the names. Alternatively, the manager would wait until the researcher arrived on the pre-arranged day only to select names of his or her own choosing, on the actual day of the interview. Considering that the managers were doing the researcher a favour, it was not possible to insist on random selection.

The volunteers provided important information about themselves and the work they do as caregivers. In the case of the larger CHBC programmes it was decided to select a larger number of volunteer caregivers to represent the wide area of coverage of these two organisations. One of these organisations has caregivers operating in traditionally Coloured and African areas in both Port Elizabeth and Uitenhage. It was felt that in order to obtain a clearer picture of care in the NMBM it would be useful to select four areas and eight caregivers from this organisation. This is especially significant as no other organisation in the sample had caregivers operating in Windvogel in Port Elizabeth and KwaNobuhle in Uitenhage. There were 32 caregivers interviewed in total.

4.3.6.4 Clients

The client population group was selected from all the clients who are cared for by all the volunteer caregivers working for CHBC programmes in the NPO sample. As with volunteer caregivers, it was initially intended that the clients of each CHBC programme be selected using systematic random sampling. This was indeed done, but as with the volunteer caregivers there were certain problems along the way. Most of the managers were reluctant to provide the researcher with the names of the clients in their CHBC programme. This is understandable, but it did not help with the process of random sampling. It is important to bear two things in mind: 1) the researcher did not request the client to reveal his or her HIV status and 2) the researcher did not interview each client personally. As with the caregivers, four names were always selected in case a client had to go to the clinic or was sick on the day of the interview. Again, on many occasions, the people who were finally interviewed were not on the list of randomly selected names. The clients were interviewed in their homes. A weakness of such a situation was that the client was often not informed in advance that he or she was going to receive a visitor on a particular day. This situation proved frustrating, but it illustrated one of the difficulties of doing research in the community, as there is much unpredictability in the research process. Altogether, 32 clients were interviewed.

The client interviews provided the researcher with a greater understanding of the care being received by the clients from their volunteer caregivers in the NMBM. The idea was not to check-up on individual caregivers, but rather to obtain an overview of the care being provided and being received by caregivers and clients respectively in the NMBM.

4.3.6.5 Key informants

The key informant population (also the sample frame) was made up of people in the NMBM who are in some way linked with the care of clients such as clinic nurses, community and church leaders, and politicians. This sample was based on selected information gathered from people who work in the field. The key informants consisted of people who were able to provide varying perspectives on volunteer caregivers and CHBC. These interviews were necessary in order to gain insight into the needs and experiences of the volunteer caregivers.

4.3.6.6 Focus group interview participants

Statistical “representativeness” is not the aim of focus group research. Focus group researchers use “qualitative sampling” (Kuzel, 1992) “in order to encompass diversity and compose a structured rather than random sample, guided by the particular research questions which they are addressing” (Kitzinger & Barbour, 1999, p. 7). The researcher wanted the first focus group interview to consist of experts in the field of CHBC. Through the researcher’s fieldwork and interactions with people involved in community work, especially CHBC, it was possible to meet many experienced people. From these, six participants were selected to take part. Focus group interview texts generally advise researchers to choose groups of between six and eight participants (Bloor, Frankland, Thomas & Robson, 2001), with others suggesting between eight and twelve (Stewart et al., 2007). However, smaller groups may be advantageous with a complex topic or if the group consists of experts or people in authority who might take offence if not given sufficient time to express their opinion (Morgan, 1995, as cited in Bloor et al., 2001). Bloor et al. (2001) and Stewart et al. (2007) warn that groups consisting of a small number of individuals can potentially result in limited discussion and are at risk of cancellation if just one or two participants fail to turn up. This was a risk that the researcher was prepared to take because if all eight participants arrived on the day, the group would be too big for what the researcher required.

Of the six who were invited, four arrived on the day. Of the two who could not attend, one had an emergency work commitment and the other (who was away in Mthatha the week before) fell sick. This was unfortunate as both of these participants were working for the local government. One was a nursing sister working for a clinic and the other for the Department of Social Development (DSD). However, the group turned out to be cohesive and very dynamic, despite its small size, and the attendees all had much to contribute. If all six people who were invited had attended, not all the participants may have had a chance to speak at any great length.

The group consisted of: 1) a social worker who is a manager of a CHBC programme for a large faith-based organisation (FBO); 2) a former manager/director of an NPO who ran a CHBC programme, and who now works for the Family and Marriage Society of South Africa (FAMSA); 3) a former community nursing sister, now working for a university, who had previously worked at a haven as a matron for AIDS orphans and terminally ill adults and 4) a youth co-ordinator/supervisor/trainer for a large NPO with a CHBC programme.

Focus Group Interview 2 consisted of all the retired nurses who interviewed all the caregivers and clients in the study. This group consisted of four people. As the researcher was constantly in touch with them, there was no difficulty in arranging to meet with them. The purpose of this focus group interview was to obtain the thoughts of the interviewers concerning their experiences of interviewing the caregivers and clients. Therefore, this group also consisted of a panel of "experts."

4.4 Data collection

The primary means of acquiring data was through qualitative methods, in line with a phenomenological study. Data collection included semi-structured interviews, focus group interviews, structured interviews using questionnaires and self-administered questionnaires. These last two questionnaires contained many open-ended questions.

The secondary means of obtaining data in this study was through closed-ended questions, which is essentially a quantitative method. Most of the quantitative questions had the aim of acquiring descriptive statistics, to provide contextual background on participants although inferential statistics were applied to lesser degree owing to the relatively small population samples. The quantitative questions were inserted in the caregiver, client and supervisor questionnaires. Hence, the caregiver, client and supervisor questionnaires all contained quantitative and qualitative questions or, more specifically, closed and open-ended questions.

4.4.1 Interviews

Janesick (1998) defines an interview as "a meeting of two persons to exchange information and ideas through questions and responses, resulting in communication and joint construction of meaning about a particular topic" (p. 72). Three types of interview were used: 1) a structured interview, which consisted of structured open- and closed-ended questions and was used with the managers, caregivers and the clients; 2) a semi-structured interview, which was used with the key informants and 3) a focus group interview, which consisted of semi-structured interviews with open-ended questions.

4.4.1.1 Manager interviews

The first interviews were with the managers of the NPOs. The aim was to provide contextual information on the organisation, its staff members and volunteers, taking into consideration its history, the size of the volunteer workforce, and the size of client-base. The researcher interviewed each manager with a structured questionnaire with mostly closed-ended questions, but with a few open-ended questions as well. Another important reason for interviewing the managers was to request and obtain permission from them to conduct the study on their premises and with their supervisors, caregivers and clients. On only one occasion was this request denied. See Appendix B for the interview schedule for the NPO managers.

4.4.1.2 Volunteer caregiver interviews

The volunteer caregivers were interviewed using a structured interview. The questionnaires consisted of both closed (quantitative) and open-ended (qualitative) questions. The questionnaire for the caregivers was long, consisting of 18 pages of questions. Each question was in English, isiXhosa and Afrikaans. The extra languages also contributed to the length of the questionnaire. See Appendix D for caregivers' interview schedule.

4.4.1.3 Client interviews

The clients were also interviewed using a structured interview in the form of a questionnaire. The questionnaire consisted of both closed and open-ended questions. The questionnaire for the clients was not as long as the caregiver questionnaire. As with the caregiver questionnaire, each question in the questionnaire was in English, isiXhosa and Afrikaans. Like the caregiver questionnaire, the extra languages contributed to the length of the questionnaire. See Appendix E for clients' interview schedule.

4.4.1.4 Key informant interviews

The third interview used was a semi-structured interview with the key informants. The researcher conducted these interviews, as all the key informants were fluent in English and were mostly professionals in the caring professions. The researcher used a mini cassette recorder to record each interview. These interviews had a more open-ended approach and it was best that the interviews were recorded, which made it easier to make notes and for the researcher to maintain eye contact with the interviewee (Appendix G). Hence, recording the interview encouraged a more conversational approach between the interviewer and the interviewee.

These interviews were less structured than the manager interviews although they were also semi-structured. This flexibility of structure encouraged participation and facilitated feedback as the interviewees drew on their expert knowledge. According to Appleton (1995), semi-structured interview schedules help to facilitate an in-depth exploration of key informants’ knowledge and experience. Interview schedules force the interviewer to consider what could happen in the course of the interview (Greeff, 2005) and to adjust the schedule accordingly.

Key Informant 1 worked for an organisation that provided CHBC training to volunteer caregivers. However, on the day of the interview, she asked if two other staff members could also be present at the interview. She felt that the other two members could add to the contributions made by her. So the situation had changed and the scenario was almost like a focus group interview. However, the researcher decided to adapt and allow the other two staff members to participate. In retrospect, the extra participants added to the richness of the interview as each of the three interviewees had a different and valuable contribution to make to the training process. One was a trained nurse, the other a qualified trainer and the third a trained social worker. Even though there were three people present at the interview, the researcher decided to refer to them collectively as Key Informant 1. However, in the results and analysis chapters, the individual voices are acknowledged and are referred to as Ruth (social worker), Rita (HBC trainer) and Rebecca (professional nurse). Often it is necessary to refer to their organisation as well, and the organisation is referred to as *Organisation A*.

Key Informant 2, who is referred to as Mabel, is a qualified counsellor, who was formerly employed at a hospice. She was able to provide insight into counselling in a CHBC context, especially regarding the counselling of people with HIV or AIDS. She also has a Master’s degree in theology and is an ordained minister. She therefore has both psycho-social and spiritual counselling skills and experience. Mabel is currently involved in caring for OVCs, and has started an NPO for the purpose of caring for them.

Key informant 3, referred to as Gladys, was a senior representative from the municipality who was able to give a local government perspective of CHBC. This proved useful as Gladys was a qualified medical doctor and also had a keen interest in CHBC.

Finally, Key informant 4, referred to as Beulah, is involved in AIDS-related work and runs her own NGO, which acquires funding from overseas donors, which is then allocated to CBOs and NPOs that desperately need the funding. Therefore, she is aware of the strengths and weaknesses of NPOs that run CHBC programmes. She is also very aware of the impact of AIDS on the many communities with whom she works.

4.4.1.5 Focus group interviews

In this study, two focus group interviews were used with the primary purpose of “learning how respondents talk about the phenomenon of interest” (Stewart et al., 2007) with a view to understanding the concept of quality CHBC, and also for “illustration . . . or conceptualisation” (Greeff, 2005, p. 300), in order to develop a deeper understanding of what caregivers do. Focus group interviews were used in this study to obtain general background information, to stimulate new ideas and to generate impressions of CHBC (Stewart et al., 2007). Barbour (2007) also refers to the use of panels of experts, who can play a valuable role by creating guidelines and protocols regarding issues about which there is uncertainty. In this thesis, both focus group interviews consisted of panels of experts. The first focus group interview consisted of people who were experts in CHBC. The purpose of this group was to assist the researcher to gain a deeper insight into CHBC, especially regarding “quality” in CHBC. The second group consisted of the retired nurses who conducted the interviews with the caregivers and the clients. Their experience with conducting the interviews, meant that they could further add to the data acquired from the interview schedules or questionnaires.

The venue chosen for the first focus group interview was centrally located in Newton Park, Port Elizabeth. It was in the offices of a local NGO who allowed the use of its premises. The interview was recorded on both a mini cassette recorder and also on a digital voice recorder. Furthermore, an experienced secretary was appointed to record the events by hand. This was primarily to act as a backup in the event that the recording devices should break down. The focus group interview was not for the purposes of analysing the participants, but for analysing what they had to say about a particular topic.

The researcher was the facilitator of the focus group discussion. This focus group, which consisted of a panel of CHBC experts, was particularly interactive, and did not require much prompting from the facilitator. Furthermore, most of the participants knew at least one or more of the other participants through their work in CHBC.

The researcher compiled a series of questions in a semi-structured interview schedule as preparation for the focus group. Only open-ended questions were used, to encourage discussion, and the group was not asked any “why” questions (Greeff, 2005). As the group members were familiar with the topic, it was only necessary to present a short introduction to the purpose of the focus group interview. The “rules” of the discussion were explained, namely: 1) do not talk to the facilitator but the group and 2) only one person to speak at a time (see Appendix F).

The venue for the second focus group was situated in Missionvale, which was fairly central in relation to the residences of the retired nurses and therefore conveniently located. The researcher went to fetch three of the retired nurses to bring them to the venue and one drove herself. This ensured that all the participants attended the focus group interview. The venue was provided free of charge, which was a further motivation. The interview was recorded on both a mini cassette recorder and also on a digital voice recorder.

The researcher was the facilitator of the discussion. This focus group interview, which also consisted of a panel of CHBC experts, was less interactive than Focus Group Interview 1, and required much prompting from the facilitator. This was despite the fact that all the participants knew each other, either through CHBC work or through working on this project as interviewers. The same procedure was used for Focus Group Interview 2 as for Focus Group Interview 1 with regard to the preparation and questioning.

4.4.2 Self-administered questionnaires

The supervisors were asked to complete the questionnaires themselves. It was assumed that because they were nurses, their literacy skills would enable them to complete the questionnaire easily. Furthermore, the questionnaire was much shorter than the other two questionnaires, consisting of six pages (see Appendix C).

4.4.3 Data coding analysis

The researcher transcribed the four recorded key informant interviews and the two focus group interview sessions. The data was recorded in a script format and then analysed as one would analyse texts and documents. Furthermore, the qualitative data obtained from the caregiver and client interviews were added to the key informant and focus group interview data, as well as the qualitative data from the supervisor questionnaire. Tesch's coding was used to analyse the transcribed data (Creswell, 2003). A multitude of topics were identified and from these topics eight sub-themes were generated. These sub-themes were then gathered under three main themes: 1) Socio-economic factors and their effects on the quality of CHBC; 2) Support received by clients and caregivers within and without CHBC organisational structures and its influence on quality CHBC and 3) Addressing structural challenges to improve the quality of CHBC

4.5 Trustworthiness

According to Lincoln and Guba (1985), good qualitative research depends heavily on the concept of trustworthiness. They list four main criteria on which to determine whether a study can be regarded as trustworthy, namely: credibility or truth value, transferability or applicability, dependability or consistency and confirmability or neutrality (Babbie & Mouton, 2006). De Vos (2005, p. 346) states that "every systematic enquiry into the human condition must address these issues." Trustworthiness can be achieved by using "multiple methods of data collection, such as observation, interviews and document analyses" (Nieuwenhuis, 2007, p. 80). Creswell (2003) identifies eight primary strategies that are closely linked to the four criteria listed by Lincoln and Guba (1985). He notes the following strategies: triangulation; member-checking; rich, thick description; clarifying researcher bias; highlighting discrepant information; prolonged time in the field; peer debriefing and the use of an external auditor (Creswell, 2003). A qualitative study need not make use of all the strategies listed, but it can use two or three to strengthen the validity of the research.

The first strategy identified by Creswell is that of triangulation. According to Patton (1999), triangulation means using a variety of methods during data gathering and analysis. This increases the trustworthiness of research. As Patton (1999) says, "Because each method reveals different aspects of empirical reality, multiple methods of data collection and analysis provide more grist for the research mill" (p. 1192). Furthermore, another benefit of triangulation is that there is less chance that conclusions will reflect the bias or limitations of a certain method (Maxwell, 1996).

This study made use of a variety of sources that provided insights into the same topic, namely volunteer caregivers and CHBC services and the people who are the recipients of such services. By obtaining the views of the supervisors, who guide the volunteers in their work, together with the views of the clients who receive their services, the researcher was able to obtain multiple perspectives of the same subject matter. Furthermore, the views of the key informants and the focus group interview participants all contributed towards a deeper understanding of the topic.

Throughout the discussion and findings chapter (Chapter 5) frequent use of large direct quotes from the participants will be used to "convey the findings" to the reader. When quotes of this nature are used in the discussion it has the potential to bring about a sense of "shared experience[ ]" on the part of the reader, resulting in what Creswell (2003) describes as "rich, thick description" (p. 196).

To add to the trustworthiness, an independent coder (Creswell's external auditor) was asked to apply Tesch's coding system to the transcribed qualitative data obtained from the one-on-one interviews, the focus group interviews and the qualitative data from the caregiver, client and supervisor interviews (see Appendix H).

4.6 Ethical considerations

Terre Blanche, Durrheim and Painter (2006) highlight the importance of four basic ethical principles that researchers should adhere to, namely: autonomy and respect for the dignity of persons; non-maleficence; beneficence and justice (pp. 67-68). Autonomy is essentially the need to make provision for informed consent in a study, thus giving participants the opportunity to accept or reject taking part in a study. Non-maleficence concerns the need for the researcher to ensure that no harm comes to the participants in his or her study. Beneficence refers to the researcher striving to maximize the possible benefits that a participant could gain from taking part in the study. Finally, justice requires the researcher to treat the research participants with fairness and equity over the duration of the study.

Before the commencement of the fieldwork in this study, ethics approval was sought and received from the NMMU Research, Technology and Innovation (RTI) committee. Ethical approval ensured that the research methods used were in accord with the ethical standards as laid out by the university. Furthermore, permission was requested from all the NPO CHBC programme managers to conduct research on themselves, staff, volunteer caregivers and clients.

All the participants, key informants, managers, supervisors, volunteer caregivers, and clients were asked to sign a consent form to indicate that they were willing to participate in the study. The consent form indicated that they were guaranteed confidentiality. The consent form had a brief statement of the aims, procedures and possible applications of the research so that respondents could make an informed decision. The focus group interview sessions were recorded using digital and analogue recorders with the permission of the participants.

The interviewers (retired nurses) were instructed to make sure that all the respondents were aware that they had the right to terminate their participation, refuse to give information or to ask for clarification about the purpose of the study. All participants were voluntary and were not coerced. At no stage were consent forms and interview schedules connected by means of a name. A master identification file was created to link numbers to names, to permit the later correction of missing or contradictory information. This file was kept under lock and key. Hence, confidentiality was guaranteed. However, anonymity could not be guaranteed, since the interviewers would be collecting the information from an identifiable respondent (Babbie & Mouton, 2006).

A further ethical consideration was not upsetting participants. The questions in the supervisor interview schedules were primarily about the volunteer caregivers and their relationship with the volunteer caregivers under their care, thus the interviews were not of a sensitive nature. In the case of volunteer caregivers, care giving is a stressful occupation and some of the volunteer caregivers may have been under stress, especially if they were caring for one of their own family members who may have been in the terminal stages of AIDS. A further possibility was that some of the volunteer caregivers may have had AIDS themselves. However, the volunteer caregivers were at no stage asked about their status.

The caregiver interviews took place in familiar surroundings, such as the offices' of the NPOs that run the CHBC programmes. Most of the questions were not of a sensitive nature, despite being personal.

The clients were interviewed in their homes and were not asked any questions about themselves directly. They were not asked to reveal their HIV status and most of the questions were related to the volunteer caregivers who cared for them. Retired professional nurses, with counselling skills, interviewed both the caregivers and the clients. This ensured that in the event that the participants needed counselling, it was available to them.

Research should always aim to be directed at improving the well-being of the participants, and should not cause any harm (Katzenellenbogen, Joubert & Abdool Karim, 2002). The degree of risk to the participants was minimal, especially as they could withdraw from the interview process at any time. The results of the study will be made available in written format for whoever would like to read them.

4.7 Biographical data of participants

This section presents the biographical details of the supervisors, volunteer caregivers and the clients of the volunteer caregivers. The biographical details of each group of participants are presented in a table format at the end of each section.

4.7.1 Supervisors

Details regarding the supervisors' length of time that they had been working at their respective CHBC organisations are presented. Furthermore, gender, age, marital status, education, population group, language group, religion, employment status and income bracket are also discussed below.

4.7.1.1 Length of time with the CHBC organisation

The supervisors have on average been working for their agencies for 5.6 years each. This demonstrates commitment and will be beneficial to the agencies in this sample, because it provides stability and support to the organisation and the caregivers in the organisation.

4.7.1.2 Gender

There were 15 female supervisors and one male supervisor. This appears to be trend with regard to HBC, whereby women play a major role in providing care in the communities (Akintola, 2006; Lindsey, Hirschfeld, Tlou, & Ncube, 2003).

4.7.1.3 Age

The average age of the supervisors was 53.71 years per supervisor, suggesting that they may have life experiences which they could share with their volunteers.

4.7.1.4 Marital status

Ten of the supervisors (62.5%) were married, one divorced, three widowed, one single and one supervisor left the answer missing. If one combines the widowed supervisors, it demonstrates that 81 per cent of the supervisors were married. The marital status of the supervisors is set out in Table 4.3.

4.7.1.5 Education

Half of the supervisors had a tertiary education, with four having selected Grade 10 – Grade 12. Two said they had Grade 8 – Grade 9 and two did not answer. This is problematic for two reasons: 1) people with a lower education do not necessary have the skills to make an effective supervisor and 2) over half of the supervisors are not professional nurses or retired health professionals. In order for CHBC to be successful it is important that the people in management positions are equipped to guide the caregivers with their care work. They also need the authority to make judgement calls and they need to have a standing in the community (Cameron, 2003 and WHO, 2002). Furthermore, the relationship between the CHBC organisations and the clinics will be stronger if the supervisors are nurses, because the clinic nurses are more likely to respect supervisors who have the same qualifications as them (see Table 4.3).

4.7.1.6 Population groups and language

Thirteen of the supervisors were African and three were Coloured. Three had English as their main language at home and thirteen had isiXhosa as their main language at home. The three English speakers are also fluent in Afrikaans and one is also fluent in isiXhosa. The two who are Afrikaans speakers work in areas that are predominantly Afrikaans speaking so the problem of language or communication is reduced. These statistics on population and language group, as well as the above-discussed statistics relating to marital status and education levels are tabulated below in Table 4.3:

Table 4.3: Supervisors: Marital status, education levels, population and language groups

MARITAL STATUS	**No. of supervisors**
Married	10
Divorced	1
Widowed	3
Single/never married	1
Not specified	1
EDUCATION LEVELS	
Supervisors with tertiary education	8
Supervisors who have Grade 10 – 12	4
Supervisors who have Grade 8 – 9	2
Supervisors who did not specify	2
POPULATION GROUP	
African	13
Coloured	3
LANGUAGE GROUP	
IsiXhosa	13
English	3

4.7.1.7 Religion

All the supervisors said that they were Christian and all said that their faith was "very important" to them. Again, it appears that the link between Christianity and volunteering is close, as most of the supervisors are volunteers at their respective agencies. Another benefit of the fact that the supervisors are Christian is that majority of caregivers are Christian, which means when it comes to spiritual care the two groups can identify with each other and understand where they are coming from.

4.7.1.8 Employment and income status

Twelve supervisors said that "no" they were not employed outside the CHBC organisation. Two said "yes" they were and two did not specify. Five of the supervisors said they were formally employed, four casually employed, three were pensioners, and two were unemployed. One indicated "other" and another did not answer. These answers need to be clarified by stating that only three of the supervisors are employed by their respective CHBC organisations. Hence, of the five caregivers who said they were formally employed, two were employed outside of their CHBC organisation. Five supervisors (31.25%) earn above R3000 per month, five (31.25%) earn between R2001 and R3000 per month, one earns between R1001 and R2000 per month and three earn between R501 and R1000 per month. Two never answered the question.

4.7.2 Caregivers

Details regarding the volunteer caregivers' length of time that they had been working at their respective CHBC organisations are presented. In addition, the caregivers' gender, age, marital status, education, population group, language group, religion, employment status and income bracket are also presented below.

4.7.2.1 Length of time with the CHBC organisation

The average length of time that each caregiver had worked at their respective organisations was four years. The maximum number of years worked by a caregiver for their organisation in this sample was eight years.

4.7.2.2 Gender

Most of the caregivers in this sample were female (n=25), with only seven of the caregivers being men. Akintola (2006) notes that most caregivers in Africa are female, and that in African culture women are expected to do the caring.

4.7.2.3 Age

The average age of the caregivers was 43 years with the oldest being 72 and the youngest being 34. This is contrary to the general trend where two thirds of volunteer caregivers are shown to be elderly people (Juma, Okeyo & Kidenda, 2004).

4.7.2.4 Marital status

Out of the 32 caregivers, seven were married and 17 were single and six were widowed with two participants not indicating their marital status on the questionnaires. If one groups the widowed and the single caregivers together the cumulative percentage is 71.88 per cent out of the total number of caregivers in this sample.

4.7.2.5 Education

Twenty-one of the caregivers were in the category Grade 10 – Grade 12 and five were in the category Grade 8 – Grade 10. Four were in the category Grade 4 – Grade 7 and one was in the category Grade 0 – Grade 3. One caregiver did not indicate his highest level of education. Of the 32 caregivers, 81.25 per cent had a secondary school qualification. This is important, especially regarding the monitoring process, which requires the caregivers to provide basic information about their clients and the number of visits undertaken each month. It is also a factor that influences the caregiver’s ability to take part in training and fully understand the course content. Of the caregivers, 65.63 per cent had a school qualification of at least Grade 10. Table 4.4 sets out the education levels of the caregivers.

4.7.2.6 Population groups and language

The sample consisted of 29 African and three Coloured caregivers. Of these, 28 were isiXhosa speaking, three were Afrikaans speaking and one was Sesotho speaking, indicated as “other” (see Table 4.4).

4.7.2.7 Religion

All 32 caregivers indicated that they were Christian and all considered their religion to be either “important” (n=2), or “very important” (n=30). The first hospitals, as we know them today, were begun by Christians as long ago as the fourth century (Retief, 2006). Furthermore, Christianity is closely linked to the concept of volunteering, and most of the caregivers in the organisations in this study are considered to be volunteers.

4.7.2.8 Employment and income status

Regarding unemployment, only seven of the 32 caregivers interviewed indicated that they were formally employed, while two indicated that they were casually employed. Two said that they were pensioners and the others indicated that they were either unemployed (n=5), or “other” (n=12). Four caregivers did not answer the question. Nine of the caregivers who selected “other” indicated that they were volunteers. Hence, 72 per cent of the 32 caregivers (n=23) did not have permanent work and therefore did not have a stable income. This percentage does not include the two pensioners who had fixed incomes, albeit very small amounts. Only three of the seven caregivers, who indicated that they were permanently employed, earned more than R1000 per month.

Table 4.4 shows the monthly household income of the volunteer caregivers who participated in this study. Only 9 caregivers (28%) earned more than R1000 per month, with 26 (81%) receiving household incomes of less than R2000 per month. Twelve (37.5%) were receiving less than R500 per month and 19 (59%) receiving less than R1000 per month. Clearly, these caregivers were not financially secure.

Nine caregivers (28%) said that they received a salary with an average of R1450 per month. However, judging by the “salaries” that these caregivers received, it appears that a number of caregivers regard their stipend as a salary. Furthermore, based on interviews with the managers, the researcher is aware that most of the caregivers are on stipends. In fact, only two caregivers received a salary. This clearly shows that many caregivers consider their stipend to be a salary. However, a majority of caregivers (72%) indicated that they did not receive a salary.

Seventeen of the caregivers (53%) said that they received a stipend, and this amount averaged at R408 per month per caregiver. The minimum stipend was R100 and the maximum R900. Six caregivers indicated that they received neither a stipend nor a salary. This figure is based on the number of caregivers indicating "yes" that they received a salary minus number of caregivers indicating "no" they did not receive a stipend.

Linked to stipends is the time spent volunteering. Each caregiver spent an average of 5.23 hours per day doing care work. The highest number of hours spent caring was eight hours per day with six of the caregivers spending this much time caring, while the lowest number was one hour per day.

Table 4.4 Caregivers: Marital status, education levels, population and language groups and income status

MARITAL STATUS	**No of caregivers**
Married	7
Widowed	6
Single	17
Marital status not indicated	2
EDUCATION LEVEL	
Grade 10 – 12	21
Grade 8 – 9	5
Grade 4 – 7	4
Grade 0 – 3	1
Education level not indicated	1
POPULATION GROUP	
African	29
Coloured	3
LANGUAGE GROUP	
IsiXhosa	28
Afrikaans	3
Other languages	1
INCOME STATUS	
1 – 500	12
501 – 1000	7
1001 – 2000	7
2001 – 3000	1
Above 3000	1
Other	3
Not specified	1

4.7.3 Clients

Details regarding the length of time the clients’ volunteer had been caring for them, the clients’ gender, age, marital status, education, population group, language group, religion, employment status and income bracket are presented below.

4.7.3.1 Length of time caring for client

The average number of months that a client was cared for by a caregiver was 23 months. The longest a client has been cared for was five years, while the shortest was one month. Furthermore, 15 clients (47%) had been cared for by their caregiver for more than two years. The above figures indicate a certain amount of constancy regarding the care that was being provided by the caregivers to the clients in this study.

4.7.3.2 Gender

Of all the clients in the sample, 81 per cent (n=26) were women. It is difficult to determine why such a high number of the clients were women. Although, it is known that there are more women than men who have HIV and AIDS. However, one cannot be certain whether all the women in the sample had tested positive for HIV.

4.7.3.3 Age

The average age of the clients was 49.7 years. There were five elderly people who were interviewed whose ages ranged from 79 to 88. Hence, the average was somewhat skewed because of them. If one takes the other 25 interviewees (two never gave their age) then the average age is 40. This study was about CHBC and includes all types of sick or disabled people, as stipulated by the DoH *National Guideline on Home-Based Care / Community-Based Care*, not only PLHAs.

4.7.3.4 Marital status

The majority of clients (n=19) had never been married, namely 59 per cent. Six were widowed, which is 19 per cent of the clients and one was divorced. The number of single clients was 26 or 81 per cent. It may be that those people who need outside care assistance are primarily single as there are no immediate family members to assist them. Another possible reason is that as mentioned with the caregivers, people cannot afford to marry, so it is more a cultural dilemma. The marital status of the clients is reflected in Table 4.5.

4.7.3.5 Education

Fourteen clients (43.8%) said they had a school education of Grade 7 or less, with one having had no formal education. Three indicated their education was between Grade 0 and 3 and 10 between Grade 4 and 7. Eighteen clients had a high school education, with 12 indicating that their education was between Grade 8 and 9 and six indicating that their education was between Grade 10 and 12 (see Table 4.5).

4.7.3.6 Population groups and language

Twenty-seven of the clients (84.4%) indicated that they were African and five (15.6%) indicated that they were Coloured. The language distribution was the same with 27 clients speaking isiXhosa and five speaking Afrikaans. The population and language groups are indicated in Table 4.5.

4.7.3.7 Religion

Twenty-nine of the clients (90.6%) stated that they were of the Christian religion. Twenty-six of the clients (81.2%) said that their faith was “very important” to them and five (15.6%) said it was “important” to them. This compares favourably with the caregivers who were also predominantly Christian (see Table 4.5).

4.7.3.8 Employment and income status

Thirty (93.75%) clients had a household monthly income of R2000 or less. Thirteen (40.6%) indicated that they had a household monthly income of between R1001 and R2000 per month, eight (25%) had a household monthly income of between R501 and R1000 and nine (28.1%) had a household monthly income of between R1 and R500 (CQ.A14). The fact that seventeen clients had household monthly incomes of less than R1000 demonstrates the poverty of the clients. This figure is the household income, which is needed to sustain a household and is very little if one considers that there are on average 5.23 people living in each dwelling in this client sample. **Table 4.5** below indicates the income status of the clients.

Table 4.5 Clients: Marital status, education levels, household income, population, language, and faith

MARITAL STATUS	**No. of clients**
Married	3
Widowed	6
Single	19
Cohabiting	2
Divorced	1
Did not indicate marital status	1
EDUCATION LEVEL	
Grade 10 – 12	6
Grade 8 – 9	12
Grade 4 – 7	10
Grade 0 – 3	3
No formal education	1
POPULATION GROUP	
African	27
Coloured	5
LANGUAGE GROUP	
IsiXhosa	27
Afrikaans	5
FAITH GROUP	
Christian	29
Religions other than Christian	2
No religion	1
IMPORTANCE OF FAITH	
Clients whose faith is very important to them	26
Clients whose faith is important to them	5
Clients whose faith is not important at all	1
HOUSEHOLD INCOME	
1 – 500	9
501 – 1000	8
1001 – 2000	13
2001 – 3000	1

4.8 Conclusion

This chapter explained how the research is underpinned by phenomenology as it aims to acquire a better understanding of CHBC volunteer caregivers by looking at CHBC through their eyes. Thereafter, Chapter 4 discussed how the questionnaires consisted of both qualitative and quantitative questions, based on a range of literature relevant to CHBC. The chapter also covered the way in which the research took place and described the interviewer-fieldworkers who conducted the interviews, the selection of the CHBC programmes which were part of the research, the study participants and the sampling process. The process of data collection and analysis was followed by an explanation of the steps followed to ensure that the study was conducted in a way that ensured trustworthiness and compliance with ethical considerations.

CHAPTER 5

RESULTS AND DISCUSSION

5.1 Introduction

Chapter 5 presents the three main themes that were derived from various sub-themes that emerged from an analysis of the data. The open-ended questions addressed to the participants in the study aimed to elicit answers that would lead to an understanding of the main research question: *"What is quality community home-based care (CHBC)?"*

As already mentioned, the theory or lens through which the data is analysed is social capital theory and each sub-theme is discussed with this theory in mind. Furthermore, the sub-themes helped to shed new light on quality care which is referred to throughout the chapter. The three themes were developed from a number of sub-themes and these are described in the introduction of each theme.

5.2 Theme 1: Socio-economic factors and their effects on the quality of CHBC

This theme investigates the socio-economic factors that affect CHBC and all its relevant role players. It is underpinned by two main sub-themes, namely the socio-economic factors of poverty and unemployment and the accompanying need for compensation for volunteer caregivers (VCGs). Under poverty, poor living conditions and lack of food security are discussed. Under unemployment, the reasons why people choose to volunteer are examined, especially in relation to the desire for financial reward. Linked to this sub-theme is the second sub-theme, the issue of stipends.

5.2.1 The effects of poverty on quality CHBC

This sub-theme describes key issues that result from poverty, namely poor living conditions and the lack of food security.

- **Poor living conditions**

This section discusses the problem of poor living conditions which is a direct result of poverty. First, the reality of poor living conditions for the participants in this study is presented. Second, this reality results in the clients being vulnerable to opportunistic diseases. Third, such poor living conditions make it difficult for VCGs to provide quality care and these living conditions have an impact on social capital, which in turn affects the quality of care that volunteers are able to provide.

Poor living conditions are a reality for many of the participants, both caregivers and clients, in this research. Despite the South African government's coordinated programme to fight poverty, in the form of the "War on Poverty Campaign" (South African Government, n.d.) poverty is still a widespread issue. The problem of poor living conditions was emphasised by **Belinda** in Focus Group (FG) 2, who mentioned that some of the clients whom she visited when conducting the interviews for this project lived in very poor and unhygienic conditions. **Alice** (FG2) agreed and said that she was used to these and that she encountered such unhygienic conditions all the time. The fact that 17 clients in this study had household monthly incomes of less than R1000 demonstrates the poverty of the clients. Furthermore, of these 17 clients, nine (28.1%) had a household monthly income of between R1 and R500. It is important to bear in mind that this figure is the household income, which is needed to sustain a whole household and these figures are very low if one considers that there are on average 5.23 people living in each dwelling in this client sample. It is a real challenge for people living off such low incomes to ensure that their living spaces remain hygienic as they do not always have the financial means to maintain a sanitary home.

Hence, poor living conditions leave a person vulnerable to disease. The following description by **Janet** (FG2) demonstrates the impoverishment, which she witnessed when conducting an interview for this research project: *"The one in Motherwell, she was in a bad condition, that one. Because there was a little baby, and she's got no place to stay. She has not got an ID, no milk to feed baby, nothing, and she's sick. She was very sick."* **Belinda** (FG2) also witnessed similar circumstances:

> *I didn't even want to touch anything because as I walked in, there was a room. I don't know if it was a dead person, or what. It had such a stench coming out of there, like a rotten, wet musty, a very funny stench, and then there was this little lounge where everybody sat. With this depressed mother that was the AIDS client that was doing the work, and the others*

> *were sitting there. And that place was full of flies. I don't know what was in that room. It was dark, but the doors were open, but it was very bad.*

The poor living conditions of many clients have a major impact on the ability of VCGs to provide quality care (Kang'ethe, 2009). The Department of Health's (DoH's) *Policy on Quality in Health Care for South Africa* (2007) notes that: "individuals living in poverty are more likely to experience delays in receiving appropriate treatment, or to lack access to water and sanitation within their dwelling." This statement supports Kang'ethe's (2009) argument that poor living conditions hinder volunteers from conducting their work and thus providing quality care.

From a social capital perspective, quality care is impacted by poor living conditions too. For instance, it has been noted that people living in segregated low income neighbourhoods, which are associated with poor living conditions, in the United States of America (USA), with concentrated areas of poverty, are socially isolated and therefore lack social ties to working and middle-class individuals, which serve as important sources of information about access to employment (Domíninguez & Arford, 2010, p. 116). The racial segregation that came about through Apartheid had the same effect, and continues to do so, on the people living in South Africa's townships. Not only is there a lack of information about employment, but there is a lack of information about health care. Therefore, communities and individuals often operate in isolation (Lindsey et al., 2003), which means that caregivers and especially family caregivers operate in isolation too. Poor living conditions affect the social capital of people living in such situations and this in turn has a negative effect on their health thus having a negative impact on the quality of care being provided to them.

Thus, the problem of poor living conditions is a direct consequence of poverty and is a reality for many of the participants in this study, often making them vulnerable to opportunistic illnesses. In addition, such poor living conditions affect VCGs' ability to provide quality care and also affect social capital, which in turn impacts on the quality of care being provided.

- **Food security**

This section presents the problem of food security, which besides impacting on the lives of the clients of the volunteers, also places undue pressure and frustration on the volunteers themselves. Hence, poverty and the clients' lack of food indirectly affect the quality of care that the volunteers are able to provide to their clients. Furthermore, a lack of food security is also associated with a decreased degree of social capital amongst the people who are living with a shortage of food.

In general, food security is a major problem amongst the clients of the caregivers in CHBC. According to the DoH (2001), members of the informal sector, consisting of families, volunteers, caregivers and community health workers, are expected to ensure food security. However, many in the informal sector are clearly not able to do this. Food is certainly an issue for the clients of volunteers. This is evident in that 46.88% of the clients in this study mentioned the importance of their volunteers providing them with food. **Mabel** raised the concept of Maslow's hierarchy of needs. And considering the conditions that many persons living with HIV or AIDS (PLHAs) live in, this is very pertinent. Maslow (1943) stated in his classic *A Theory of Human Motivation* that physiological needs are the most pre-potent of all human needs. This led him to state the following: "A person who is lacking food, safety, love and esteem would most probably hunger for food more strongly than for anything else" (Maslow, 1943, p. 373). The fulfilment of this most basic need is for many people in South Africa an overwhelming challenge, which they face on a daily basis. Furthermore, the bill of rights in the South African Constitution includes the right to adequate food, stipulating that the state has the obligation to ensure that the right of all its citizens to access sufficient food and water is progressively achieved (Food and Agriculture Organization, 2006).

Related to this food shortage is the pressure and frustration experienced by some volunteers regarding their inability to provide their clients with food and thus quality care. The following responses demonstrate the frustration and helplessness experienced by some of the volunteers:

- *There is nothing I can give them, like food and bandages; seems they get fed up*
- *[Clients] say I talk, but I do not bring food*
- *Some houses [have] no food; difficult to take treatment*

The quality of CHBC is negatively affected when the provision of basic food requirements is not met. This is supported by **Rachel**, who said, *"Home care alone is not going to solve the problems of the patient or the person that they are caring for."* **Maria** further expressed the problem of food shortages, saying that if there is no food and *"the family's destitute, how do they care for this person that they have been left with?"* Indeed, a 1999 survey by the non-governmental organisation (NGO), Hope Worldwide, found that lack of food was the most urgent need affecting the caregiving process (Kang'ethe, 2009). Thus, lack of food in turn prevents other aspects of care from taking place effectively. For instance, as indicated in the third VCG's comment above, lack of food makes it difficult for clients' medication to be effective. In addition, studies show that opportunistic infections are more common in people with gross nutritional depletion and malnutrition (DoH, 2001; World Food Programme, 2006). Furthermore, other areas of care are also affected. For example, **Mabel** stated with regard to psycho-social care that *"counselling cannot take place if I am so dysfunctional because my primary need is not emotional, it's physical."* Thus a lack of food affects clients physically, but it can also make counselling more challenging. Marais (2005, p. 69) expressed the problem of a lack of food as follows: "When a need as elemental as a square meal goes unmet, the 'continuum of care' is effectively robbed of its meaning." Therefore, lack of food clearly affects the quality of care; this is stated explicitly by Kang'ethe, (2009, p. 27), who argued that the lack of adequate food placed severe stress on the caregiving process, in fact "driving the caregivers further into poverty and compromising the quality of care."

A study by Martin, Rogers, Cook and Joseph (2004, p. 2653) shows that high levels of social capital are associated with decreased risk of hunger, and the findings suggest that households appear to derive "protective benefits both from their own social networks and from the greater extent of shared networks throughout the community." Therefore, it can be argued that the problem of food security and hunger are to a large degree a result of low levels of social capital in the communities in which CHBC is primarily required.

This section discussed the problem of food security, which has the effect of placing pressure and frustration on VCGs. Thus, it was argued that poverty and a lack of food impacts on the quality of care that the volunteers are able to provide to their clients. In addition, a lack of food security is closely linked to diminished social capital amongst people who are living in poverty.

5.2.2 Unemployment and the compensation of volunteer caregivers

This is the second sub-theme under Theme 1: Socio-economic factors and their effects on the quality of CHBC. The following section presents the socio-economic reasons that lead people to become VCGs and whether this reasons affect the quality of CHBC they provide. These motivations are contrasted with an alternative key psycho-social motivation that was raised by the participants in order to highlight their differing influences on quality care. When financial motivations are coupled with a love of caregiving, there may be a positive effect on social capital.

- **Reasons why people volunteer to do CHBC**

Some VCGs choose to volunteer out of a desire to obtain future employment, a desire to gain a stipend from the CHBC organisation, or a love for caregiving. This latter reason, which is a psycho-social factor, has the ability to increase quality of care, but is under threat when financial factors dominate VCGs' decision to volunteer. Despite the potential negative effects on quality care when financial reasons are the main influence on deciding to volunteer, when such reasons are coupled with a love of caregiving, it could have a positive effect on social capital.

First, an important factor, that leads many people to volunteer in South Africa, is the desire on their part to obtain employment. In a study by Thabethe (2006) it was found that "…7 out of the 10 voluntary caregivers admitted that they are doing the work because it is better than sitting at home doing nothing. They maintained that if they were to find formal employment they would leave CHBC…" (p. 65). Hence, volunteering for such people is really a means to an end. Akintola (2008a) supports this idea saying: "Some people are motivated by the hope that volunteering will help them find a job in healthcare" (p. 129). This is understandable as many volunteers live in poverty and are unemployed. **Beulah** noted that people often volunteer after long periods of unemployment. She said the following:

> *Well, I'm quite a cynic around that [volunteering] as I've told you before. I honestly don't believe, in all of my years of experience now, that people are absolutely genuine. Because where people are coming forward to volunteer is where people have not been employed for a long time. . . . And we ask questions like ... and why are you doing what you're doing?' And nine times out of ten, it's because 'I'm hoping that this will be a stepping stone.'*

Rachel too stated that the *"ultimate goal for the caregivers"* is *"working towards becoming employed eventually."*

Another reason for doing volunteer care work is the desire to receive a stipend from the CHBC organisation. Seventeen of the caregivers (53%) said that they received a stipend, and this amount averaged at R408 per month per caregiver. The minimum stipend was R100 and the maximum R900. **Lucy** stated that *"if there is a stipend or there's a salary, people might just come in because of being remunerated."* This is further supported by **Gladys** who stated: *"They volunteer . . . but you find that they volunteer with the hope of being stipended at one stage or another."* **Maria** emphasised that when a stipend is introduced into the volunteer-CHBC scenario then the focus of the caregiver appears to shift, because the stipend is seen by volunteers as a salary. **Sophia** described how the introduction of the stipend seems to have affected the attitude of the volunteers towards caregiving and this in turn can affect the quality of the care provided:

> *With poverty and unemployment in South Africa these days, we don't really have volunteers. Because of one thing that whatever they do, there is an expectation because how else must they live? With compassion and passion, we're talking about it, yes, went through the window with the stipend.*

Two caregivers in this study admitted that they chose to volunteer with the hope of receiving financial compensation: One caregiver said that she needed the money and the other said she was unemployed and that is why she started care work. These last two examples contrasted with another reason mentioned by the other caregivers why they decided to volunteer, namely a love for caregiving. Research has suggested the latter reason has a positive effect on quality of care (Baernholdt, Jennings, Merwin & Thornlow, 2010), in contrast to volunteers motivated solely by a desire for remuneration.

VCGs in this study were motivated by a love for caregiving. Quite a high number of caregivers (13 or 41% of the caregivers), in this study, said that they volunteered in other organisations or at the same organisation, but doing other activities besides CHBC care work. It could be argued that if the caregivers volunteer their time engaging in other activities besides caregiving that perhaps there is an element of altruism at work. **Lucy** felt strongly that volunteers needed to have compassion and passion in order to be effective caregivers, noting that *"The word comes back to compassion, having the compassion for the work, because if you don't have that or even passion, then obviously you're coming in to waste the organisation's time, and you're going to mess around with the patient."* This is also supported by Baernholdt et al. (2010), who, in a study of quality in rural nursing stated that "established measures of quality care are used in rural hospitals, but most important for quality care is that patients are treated with respect and compassion from up-to-date and competent nurses" (p. 1353). Therefore, in order to provide quality care, it appears that compassion and passion are needed by VCGs. Desire for financial benefits is unlikely to produce this compassion and passion which appear so invaluable in the provision of quality care. This is expressed by **Maria**, who notes the following:

> *You go to clean up other people's—well, let's not go into graphics, but just get the visual picture of it. You can't pay people for that. You can't pay people to have compassion.*

In fact, financial motivations are likely to reduce the quality of care. A parallel is found in the medical field: According to Martin, Henderson and Charlesworth (2010), "although there is growing interest internationally in the use of financial incentives to improve the quality of care, this approach does seem to contradict some aspects of the theories . . . considered . . . about motivation. . . . Various commentators have highlighted the problems inherent in an externally driven approach involving financial rewards" (pp. 66-67). Martin et al. (2010), drawing on the work of Roland et al. (2006) and McDonald et al. (2007), go on to note how "external incentives" can cause doctors to prioritise financial benefits to themselves ahead of the patient's best interests. Furthermore, **Sarah** argued that increasing stipends or financial benefits would also not result in a direct improvement of quality of care. She argues, *"Focus on the quality of what they're doing for the money they're receiving, and from there, look at increasing [their stipends] again."* Hence, **Sarah** is arguing that one cannot increase a volunteer's pay if the quality of care that he or she is providing is not of a certain standard. In other words, if one increases a volunteer's pay and there is no corresponding improvement in care then it appears as though the caregiver is being rewarded for poor work.

However, in terms of social capital, financial reasons for volunteering may produce certain positive effects. The overall bonding social capital in the community need not be reduced as the bonding social capital within the caregivers' respective families may be increased because of the increase in financial independence resulting from stipends. In addition, Rödlach (2009, pp. 428-9) refers to Bourdieu (1986) with regard to the prestige and respect attained by caregivers for their volunteering work; thus they are exchanging time and energy for social capital. In addition, despite some caregivers' choosing to volunteer for financial reasons, when these self-serving motivations are combined with a concern for their clients, this *"'mixed-motive' cooperation"* (Uphoff, 2000, p. 230, Uphoff's emphasis) still provides benefits in the form of stronger social capital in the community where they serve as it results in what Uphoff (2000) describes as a "positive-sum" (p. 230), whereby there is reciprocity in that the caregiver gets financial remuneration and the client obtains care. Whether this care is of a sufficiently high quality, however, is debatable.

To sum up, people appear to volunteer as caregivers owing to two main factors, namely a desire to obtain employment, and a desire to gain stipends. However, a third factor was identified in the study namely a love for caregiving. It is argued that a love of caregiving has the ability to increase quality of care. When financial factors dominate VCGs' motivations, quality CHBC may be negatively affected. However, when financial reasons for volunteering are combined with a love of caregiving, it may have a positive impact on the social capital in the communities from where the volunteers originate.

5.3 Theme 2: Support received by clients and caregivers within and without CHBC organisational structures and its influence on quality CHBC

This theme focuses on the advantages of CHBC to clients and caregivers as a result of the support that clients and caregivers receive. In addition, the contribution to quality care of these types of support is discussed. The first sub-theme concerns the advantages of CHBC to the clients of VCGs and looks at counselling as a component of the holistic care provided by CHBC organisations. The second sub-theme looks at the advantages of CHBC to volunteers in their work as caregivers, discussing different forms of social support: from peers, supervisors, family, and communities.

5.3.1 CHBC benefits to clients of volunteer caregivers

This section concerns the benefits that clients garner from CHBC services. There are two aspects to consider, namely psycho-social counselling and spiritual counselling provided to clients by the caregivers, both of which form part of holistic care.

- **In addition to physical care, CHBC volunteer caregivers provide counselling care to their clients**

This section looks at an important aspect of CHBC, namely that it is holistic in nature which has added benefits to the clients because in addition to physical care, it also includes counselling. The holistic nature of CHBC also adds to the quality of care that clients receive. The counselling component has the ability to instil hope in the clients of CHBC caregivers, which also contributes to the quality of care they receive. The experiences of the clients who participated in this study are also discussed in relation to the counselling received from their caregivers. An aspect of counselling not often dealt with, namely spiritual counselling is discussed together with the need for trust and confidentiality in the caregiver-client relationship.

First, the provision of counselling by VCGs adds to the holistic nature of CHBC. The following definition of counselling comes from Van Dyk (2008, p. 219) who drew on Gillis (1994) and Sikkema and Bissett (1997):

> Counselling is a facilitative process in which the counsellor, working within the framework of a special helping relationship, uses specific skills to assist clients to develop self knowledge, emotional acceptance, emotional growth, and personal resources.

These counselling skills are an integral part of effective CHBC and owing to the holistic nature of CHBC, this emotional care operates in conjunction with physical care. For instance, **Lucy** spoke about counselling as an important aspect of holistic CHBC:

> *I think for me it's the individual attention that the patient gets, knowing that there is someone who is multi-skilled if one can put it that way where you can actually do a bit of counselling, it's not just about the caring, but also it's about looking after the body, mind and soul. . . .*

Sarah also emphasizes the importance of counselling in CHBC, noting that : *"it's important to have a counselling and a listening side, just as much as it is the actual skills of HBC [home-based care], practical bed baths and wound care and those sorts of things."* **Sarah** explained that her organisation actually expanded in response to the need for counselling.

In terms of **quality care**, the holistic nature of the care, of which counselling is a part, contributes to the quality of the care provided to clients, as is evident in the responses to the question *"Are you happy with the service that your VCG gives you (please explain)?"* which showed the range of needs to which a caregiver is able to respond. Based on the clients' answers, it can be said that VCGs provide a range of services such as referrals, cleaning/washing and applying body cream or rubbing feet, being always available and visiting, giving advice and providing transport, sharing groceries, and cooking. Clearly, these sorts of services are much more diverse than those that are provided by health care workers in government institutions, such as hospitals, thus volunteers are able to provide holistic care, which is needed by the patient.

More specifically, a link between counselling, which forms an important part of holistic care, and quality care is reflected in the literature. This is evident in research by Lindsey et al. (2003). Their study sought to identify, *inter alia*, interventions to provide quality care, and the authors indicated in their findings that in order to achieve quality care, clients and their families are in need of counselling (Lindsey et al., 2003).

A benefit of counselling is that it can help to bring hope to those people who are affected, especially young people, by the AIDS pandemic. **Mabel** explained how counselling can help to make a difference to such people who have given up hope of finding employment or having a career. She also described the problem of hopelessness very effectively using the first person pronoun as though she herself was a PLHA:

> *my need is not just not just a life-limited disease, my need is living in a world where the seeds of hopelessness kind of attack me and sometimes I feel like I'm being strangled and my greater need is just existing day to day and having enough to put in my tummy and into the tummies of my children.*

Mabel believed it was crucial to invest time and energy in counselling and care, helping people to become independent and also co-dependent, but this can only be achieved by the volunteers if they are able to instil a sense of hope in their clients. Indeed, the World Health Organisation (WHO) (2002) definition states that the purpose of CHBC is to "provide hope through high-quality ... care" (p. 6).

In the current study, the clients were not asked explicitly if they received counselling, but were asked: *"Have you been able to talk to your VCG about your problems - the things that are worrying you?"* A number of themes were identified that showed the ways in which help was given. Volunteers provided assistance and advice regarding such problems as family issues, and even finance or grant problems, to which the clients expressed satisfaction. It is not possible to determine the level of counselling provided by the caregiver, but the results show that clients do talk to their caregivers when they need help. This indicates a certain level of trust. Furthermore, the clients were asked: "*Has your VCG helped with resolving (conflict) problems with your friends and family? If yes, please give an example."* Two of the clients responded as follows:

- *[She] spoke to [my] mother and father*
- *[She helped resolve the conflict] by sitting down with my family and counselling them.*

Hence, the caregivers of two of the clients in this sample helped to counsel the clients' parents and their families. This illustrates that caregivers are able to play an important role in family counselling where there is conflict between family members regarding the illness of a client.

Another question addressed to the clients was: *"Has your VCG helped you to feel less lonely or isolated? If yes, in what way did he/she help?"* This question also elicited responses that helped indicate whether counselling was actually taking place. In response, the clients spoke about the caregivers talking to them; giving them advice; encouraging them; and comforting them. Hence, a more informal form of counselling appears to be taking place here: The regular visits where an exchange of advice, encouragement and comfort is taking place, suggests that there is a degree of counselling, in the form of psychological or emotional support.

Another form of counselling is spiritual counselling. **Rachel** said that an important aspect of quality care is the need for spiritual support of the client. When asked about quality care, one of the supervisors also mentioned the importance of spiritual support. As already indicated, **Lucy** stated the importance of VCGs' taking care of not only body and mind but also the soul. **Mabel** also emphasised that spiritual care has *"a huge role ... to play. . . . It is an unfolding of grace . . . which then begins to change me from the inside out so the way spiritual care is offered is often more important."* However, **Mabel** noted that spiritual counselling needs to be undertaken with care, warning that counsellors need to be careful how that spiritual care is offered, stressing the need for the caregiver to show the client respect when providing spiritual care. **Mabel** also highlighted how religion had sustained many people during the years of oppression under apartheid, a fact which suggests that it can also assist people through the socio-economic hardships of post-apartheid South Africa. According to her:

> *...it does have a tremendous role... look at how in all of that darkness people clung to what they believed. To something beyond what we can put in words and it is a force, an almighty force for peace.*

The clients were asked the following question related to spiritual care: "*Has your carer helped you get spiritual (religious) comfort? If yes, in what way did they help?*" In response sixteen of the clients referred to prayer either for or with them, some mentioned Bible study and others church attendance. Two clients used the word "counselling" in conjunction with prayer. This indicates that almost all the clients agreed that their caregivers provided them with some degree of spiritual support. Turning to the caregivers, all except one said that they provide their clients with spiritual support.

The fact that the clients receive spiritual support demonstrates once again the holistic nature of CHBC. Furthermore, the responses of the participants indicate that spiritual supports adds to the quality of care that is received. Despite these positive responses, in order for spiritual care to be effective, it must be presented in the right way. **Mabel** warns that while spiritual care is beneficial, *"we need to be ever so careful about how we use that cement. Unfortunately, like anything that is good, there can be abuse."* Thus, **Mabel** emphasized that spiritual support needs to be presented in a careful, gentle manner.

The vital role of trust in counselling was emphasised by **Mabel** too:

> *What brings healing we need to ask ourselves? It's ultimately allowing ourselves to trust both ourselves and the other person to be a conduit of grace. And if I can trust you enough because of your demeanour because of your sincerity...that I can trust you as a person I'm actually going to share with you.*

It is clear that trust is very important for spiritual counselling. Furthermore, trust is vital in all forms of counselling (British Association for Counselling and Psychotherapy, 2010.)—the client trusts the caregiver to maintain confidentiality. According to Van Dyk (2008), “confidentiality in the counselling context is non-negotiable. A counsellor may not, under any circumstances, disclose the HIV status *or any other information* to anybody without the express permission of the client” (p. 231, Van Dyk’s emphasis).

Trust falls under cognitive social capital and is linked to sharing and reciprocity (Islam et al., 2006), as demonstrated by Putnam’s (1996, para. 3) definition, which states that social capital consists of “networks, norms, and trust that enable participants to act together more effectively to pursue shared objectives.” Indeed, for spiritual counselling within CHBC, caregivers interact with their clients in a very personal way. In this study, the results on counselling appear to suggest a high level of trust, based on the positive comments made by many of the clients. This trust element is critical in strengthening social capital and the role of the caregivers in providing counselling is significant as it helps to further increase the trust levels amongst community members. On the other hand, caregivers have a great responsibility in maintaining confidentiality as they deal with very intimate aspects of their clients’ lives.

In conclusion, this section examined the holistic nature of CHBC, which in addition to physical care is an important benefit to CHBC clients, because it also includes a counselling aspect. It was noted how the holistic nature of CHBC contributes to an increase in the quality of CHBC. By counselling clients CHBC can instil a sense of hope in the clients of CHBC caregivers, which also contributes to the quality of care they receive. The experiences of the clients who participated in this study were discussed regarding the counselling received from their caregivers. Spiritual counselling was also discussed together with the need for trust and confidentiality in the caregiver-client relationship.

5.3.2 CHBC benefits to volunteer caregivers

This sub-theme deals with the four different levels of support which *CHBC VCGs receive, namely peer support*; *supervisor support*; *family support*; and *community support.* Caregivers who operate outside the organisational structures of formal CHBC programmes do not necessarily have the support they need to carry out their work. Belonging to an organisation increases the caregivers' support base as they can draw on support from peers and supervisors. Levels of family and community support also affect their ability to provide quality care within the organisation.

- **CHBC volunteer caregivers receive peer support**

This section firstly describes the support that VCGs receive from their fellow volunteers and secondly describes how this benefits the organisation and results in quality care. Thirdly, the benefits of peer support in developing strong bonding social capital are discussed after this.

Peer support was an important theme in the current research. Thirty (94%) of the caregivers said that they helped each other with their problems. Below is a list of some of the caregiver responses to the question about VCG problems and how they help each other.

- *When client has a health problem [I ask the carers] what I should do?*
- *If I have to be helped with dressing client I ask one of them*
- *When I am busy with one client and another [client] needs help they [peers] help out*
- *We share problems although we don't mention patients' names then we advise each other*
- *When we attend meetings we sit in group and share problems that we are encountering*
- *We go together to visit client especially when there is a danger in the area*

These responses highlight the value of peer support as they illustrate how team work between volunteers in CHBC can strengthen the organisation. This teamwork ranges from asking for advice (beneficial to both the client and the caregiver as they will both be better equipped to make the right decision) to substituting for fellow caregivers so that the client will have the necessary support. Help with difficult practical tasks is beneficial not only to the caregiver but may also add to the dignity of the client, by preventing any embarrassing situations from occurring. Confidentiality is a priority as the clients' personal lives need to be safeguarded, and it is reassuring to know that some caregivers take this part of their work very seriously, as evident from the fourth response. Group sharing during regular meetings will again benefit caregivers and clients. Accompanying each other into dangerous areas means safety for the caregiver and greater availability to the client.

In terms of quality care, because the support that the VCGs give one another impacts on the care that they provide to their clients, it ensures that the volunteers are able to provide the best care possible relative to their particular circumstances. Hence, peer support has an impact on the quality of care that is received by the volunteers' clients. Indeed, Dennis (2003) states that "peer support has become a significant element in the delivery of quality care" (p. 239). Morna, Ntsabane and Muzenda (2009) lend further weight behind the argument that calls for more peer support in CHBC by stating that it is necessary to "encourage peer counselling so volunteers can support one another" (p. 5).

However, despite the positive effects of peer support, Dennis (2003) does identify certain negative aspects of peer support. Using a number of sources he lists the following potential "adverse outcomes" that may result from peer support, namely "conflict, criticism, failed social attempts, emotional over-involvement resulting in contagion stress, reinforcement of poor behaviours, diminished feelings of self-efficacy, lack of stability, and 'shadow work' in which an informal, parallel economy supports the formal, market-based economy" (p. 328). It can be argued that the list presents a series of vague emotions or experiences that are difficult to identify never mind remedy. However, these negative aspects of peer support need to be considered and the formalisation of peer support could help to overcome or manage much of these experiences.

The positive peer support between VCGs is what can be referred to as bonding social capital. As mentioned in Chapter 2, bonding ties, which fall under horizontal ties, exist between individuals or groups of equals or near-equals (Islam et al., 2006) which is what the volunteers can generally be considered to be. Bonding ties foster strong norms of reciprocity, ease of communication and the flow of information about the trustworthiness of others (Putnam, 1993). The support that the volunteers give each other stems largely from these three aspects, which are closely linked to cultural commonalities, common language and the trust that comes from familiarity.

Thus, it is evident that VCGs often rely on each other for both practical help and emotional support and advice, thereby improving the service they provide and increasing the quality of care, which is also improved by the bonding social capital that develops as a result of peer support.

- **CHBC volunteer caregivers receive supervisor support**

Supervisors play a prominent role in the organisations in the current study. Caregivers' responses indicated that their supervisors provide them with psychological and emotional support. Supervisors also conduct client visits, hold meetings with caregivers and mostly speak the same language as caregivers. The majority of caregivers feel comfortable with the supervisors and the generally good relationship that appears to exist between supervisors and caregivers strengthens social capital and has a positive impact on quality care.

First, caregivers in this research clearly receive support from their supervisors. The caregivers were asked if they received psychological/emotional support from their CHBC agency and to describe the support they receive from their supervisor. Below are three of their responses:

- *The supervisor gives help.*
- *We come and tell them our difficulties and get help through our supervisors.*
- *We do prayer by [supervisor].*

Clearly the supervisors to these caregivers are a great support to them as they feel they can obtain help from them and, as indicated in the last quote, they also receive spiritual care from them.

In addition, the findings also revealed that the supervisors were active in terms of client visits. The caregivers stated that on average, their supervisors visited their clients 24 times a year. It is difficult to ascertain if the supervisors visit *each* of their clients 24 times in the year or if they visit their clients in general 24 times a year. However, either way, the caregivers indicate that their supervisors are in the field, twice a month, visiting their clients. This is certainly a very positive scenario for CHBC in the community-based organisations (CBOs) of this sample. It would be even better if this were the case for the whole Nelson Mandela Bay Municipality (NMBM).

Furthermore, the supervisors in this study hold regular meetings with their caregivers. On average, the caregivers have group meetings with their supervisors 6.2 days per month. This is just over one day a week, which is very positive, because the caregivers are then acquiring the support of their supervisors on a regular basis. In addition, twenty-one (65.6%) of the caregivers said that they were able to meet with their supervisors outside of regular meetings, while nine (28%) were not able to do so. In the case of geographically large organisations, with volunteers operating in many different townships, it is more difficult for the volunteers to meet with their supervisors, because the offices of the CBO may be far from where they live, which will mean that the caregivers have to wait for their supervisors to come to them or they must travel there by taxi. Of course they could telephone the supervisor, but this will generally not be satisfactory if the caregiver needs to ask for advice or if she or he requires counselling. It is easier for volunteers at geographically small organisations, which operate in one township alone, to meet with their supervisor, because often the supervisor is also the manager and is at the office every day. Furthermore, some organisations expect their volunteers to “clock-in” at the office before going to visit their clients. In such cases, the supervisor is normally readily available.

A further aspect of the supervisor-caregiver relationship which is evident from the findings was that most supervisors are able to speak their caregivers’ language. Almost all the caregivers (93.75%) said that their supervisors could speak their language. This is very important from a communication perspective. Language plays an important role in transmitting knowledge and with caregivers often having below average education and literacy levels, the oral medium will be the most effective means of communication.

Thus, given the above facets of the supervisor/caregiver relationship, it is not surprising that generally caregivers appeared to feel comfortable with their supervisors. This is evident in another question that the caregivers were asked regarding their relationship with the supervisor: *"Do you feel comfortable talking to your supervisor?"* Twenty-nine of the caregivers (91%) said that they were comfortable talking to their supervisors and all of these caregivers had encouraging things to say about their supervisors. Many said that they felt that their supervisor was "approachable". Others complimented their supervisors on their listening skills and said they were able to talk to their supervisors about anything. One caregiver said his supervisor was *"just like a mother to me"*, and another caregiver described her supervisor as *"like a friend to us."* If the caregivers feel that they can consult with their supervisors, normally retired professional nurses, about difficult situations concerning their clients, the clients will almost always stand to benefit. Further evidence of the good relationship between the supervisors and their caregivers was revealed in the answers to *"What are some of the issues you discuss with your supervisor?"* Twenty of the caregivers said that they discussed client problems while some also discussed personal problems with their supervisor. It is interesting that not all the caregivers go to their supervisors for counselling. Only 66 per cent indicated that they do, as opposed to the 31 per cent (n=10) who do not. Although a large majority of the caregivers said that they discussed client problems with their supervisor only some raised personal issues.

Regarding social capital, the supervisor-caregiver relationship and the supervisor-client relationships are an example of vertical social ties. Vertical social ties are also related to bridging social capital, whereby the knowledge and expertise of one group benefits another group. In this case, the supervisors, who are largely qualified nurses, have an abundance of health care knowledge which they are then able to pass on to their caregivers, which in turn benefits the clients. Hence, the social capital, from a health care perspective, is strengthened.

In relation to quality care, the support from supervisors cannot be underestimated, especially as their care for their caregivers in turn affects the caregivers' care for their clients. Of course, supervision can have negative effects, for example, if there are personality clashes or if the supervisor and the caregiver feel trapped in the supervisor-caregiver relationship (Todd & Storm, 2002).

However, the positives of good supervision far outweigh potential negatives of no supervision. This is supported by the *Republic of Namibia Ministry of Health and Social*

Services (2007, p. 45-46), which emphasises the importance of "supportive supervision" with regard to quality CHBC and the sustainability of CHBC programmes. **Sarah** also argued that if, amongst other things, the caregivers are supervised, *"HBC can be effective"*. **Gladys** stated that supervisors who are professionals are able to give the volunteers professional help and advice, because there are issues that volunteers cannot always deal with themselves. For **Sarah**, supervision, together with mentoring, was the most important aspect of CHBC. **Sophia** felt that an important aspect of a successful CHBC programme was one with supervised VCGs.

It is clear that caregivers need and appreciate their supervisors' support, which takes on a range of forms: psychological/emotional support, client visits and frequent meetings. A further benefit was that the majority of supervisors were able to communicate in the same language as their caregivers. Overall, caregivers were comfortable with the supervisors and these positive relationships in turned impacted positively on social capital and quality care.

- **CHBC volunteer caregivers receive family support**

The families of VCGs can make a difference to the effectiveness of CHBC. While caregiving can have negative effects on the caregiver's family, as discussed below, many caregivers in this research study experienced positive support. Such family support has a positive impact on quality of care and also strengthens bonding social capital.

Wainwright (2002), states that CHBC caregivers experience greater stress than professional caregivers and argues that this is largely due to among other things a lack of adequate support. Hence, if the volunteers are under stress it is possible that their stress will be transferred to their families. For instance, families of VCGs have to make certain sacrifices such as having their family member be away from home at strange hours. **Beulah** asked the question: *"What happens to their families?"* when referring to volunteers and the need to manage their working hours in order to consider their families. Having community members knocking at the door at all hours and having a spouse or mother/father who often carries the problems of his or her clients on his or her shoulders can affect family life negatively.

Another factor that can affect VCGs is the financial impact that volunteering can have on their families. The issue of financial burden on volunteers was raised in a Botswana study stating: “without remuneration, volunteers struggle to take care of their families” (Morna et al., 2009, p. 9).

However, despite potential negative impacts on families, the majority of the caregivers in this study said that their families supported them. In fact, 87.5% stated that they received support from their families. Here are a few extracts of what the caregivers had to say about the support that they received from their families:

- *They are also keen and interested in community involvement*
- *They tell me I am bringing back ubuntu*
- *They can see that I am interested in my clients so they encourage me*
- *They also help me with my clients*
- *They give me words that make me keep going*
- *They help with the housework while I’m out doing the caring work.*
- *They ask me to be strong to do the work; put God [first] all the time*
- *My children love what I am doing because they lost sister because of HIV; they know how the help is needed*

These extracts are very encouraging, because the families were clearly supportive in the care work of the VCGs. It implies that the majority of caregivers’ families in this study did not stigmatise PLHAs and they approved of community work and CHBC. If they encouraged the caregivers, they were probably proud of the work that their family member did and this would be an added motivation to the caregiver to continue with their work. It is interesting that in the second italicised response above, one family considered their family member to be “bringing back” *ubuntu*. This suggests that they also felt like **Mabel** and **Beulah** who felt that *ubuntu* is not as it was and that it needed to be revived. In addition, it was encouraging that one caregiver said that her family members helped with the housework while she was out doing CHBC. This is a good example of how family members play an important role in the CHBC project.

Furthermore, the support that caregivers receive from their families has an impact on the quality of care received by their clients; if their families support them and what they are doing, it makes it that much easier for them to carry out their work. The following quote from the Joint United Nations Programme on HIV/AIDS (UNAIDS) (2007, p. 23) supports this link between support from the caregiver's family and the caregivers' ability to provide effective care:

> A survey titled "Care giving in the United States" estimates that more than 44 million Americans are unpaid caregivers, and a majority of them currently work or have worked while providing care. The survey also found that God, family and friends were most often cited as sources of strength by people who are caring for others.

The social ties between VCGs and their families constitute bonding social capital (Ferlander, 2007). One of the benefits of bonding social capital is that it enables the "transmission of behavioral norms to family members and friends" (Islam et al., 2006, p. 6). According to Cullen and Whiteford (2001), bonding social capital "can be important for the diffusion of information, establishing health norms, controlling deviancy, generating mutual aid, and protecting the vulnerable" (p. 9). Based on the preceding quote, CHBC volunteers who come from families with strong social capital will more likely feel a desire to take care of the vulnerable. As mentioned previously, the motivation behind volunteering may influence the quality of care provided by the volunteers. It takes a passion for people to motivate a person to care for the vulnerable and as mentioned earlier, caregiving that is accompanied by passion is an important element in quality care.

In summary, although CHBC can place families under strain, most caregivers in this study reported positive support from their families. This support has been shown to correlate positively to quality care and strengthens bonding social capital, which in turn increases caregivers' desire to help the vulnerable.

- **CHBC volunteer caregivers receive community support**

The role of the communities in which CHBC takes place is very important. First, communities can play a key role in enabling caregivers to obtain caring work. In addition, the current study indicates that the communities where the participants reside encourage them in their caregiving work. This support has been shown to benefit quality care, as opposed to negative community involvement, in the form of stigma. Therefore, communities have the potential to influence caregivers and CHBC positively or negatively. Furthermore, community involvement also affects social capital, which in turn may increase quality care.

Caregivers may begin working for CHBC organisations as a result of information obtained from their communities. The research showed that of the 32 caregivers, 43.75 per cent of them learnt about their care organisation from a friend, while 31.25 per cent found out about it through their church. Only 9.38 per cent (n=3) found out about their organisation through a clinic. This demonstrates two things: 1) the community aspect of the townships, especially regarding communication, where the proverbial “grapevine” is very effective and 2) the role of churches in care work in the communities is significant.

The findings indicate that all but one caregiver stated that their communities supported them in their work as VCGs. Half (n=16) of the caregivers said that they know that their communities support them because they refer clients to them. In other words, the caregivers acquire clients because the community members send prospective clients to them. This suggests that they are well known in their communities, and are accorded trust and respect which is evidence of a high level of social capital. The caregivers also said that the community members praised them for the work that they do and told them to keep up the good work. Two caregivers commented that community members bring their problems to them. These responses show that the communities where the caregivers work support them in their work. The care takes place in the community with the support of the community and the communication between community members ensures that clients are referred to VCGs and thus receive the CHBC they need.

Owing to the fact that caregivers are volunteering in the communities in which they live, Beulah stated that there is a level of trust between themselves and the community which leads to an openness that provides the clients with the necessary trust to allow the volunteers into their homes. Furthermore, she said that the volunteers know their community and that it is safe for most of them to volunteer.

Such community support can impact the quality of care provided to the clients. According to a study by Rödlach (2009), “caregivers in general were appreciated and held in high esteem” (p. 428). However, lack of community support affects the quality of care provided by volunteers: As noted in a Botswana study by Kang’ethe (2010b, p. 552) “because of their poverty, the caregivers conceded they were not able to provide what the client desired [such as food]. This was also fuelled by a lack of support from relatives, friends or community systems.” Conversely, the presence of community support increases the viability of CHBC organisations. For instance, Rosenberg et al. (2005, p. 35) noted that one of the requirements in order for a CHBC programme to be sustainable is community involvement.

However, despite these positive effects, community involvement can also negatively impact on caregivers. One negative aspect of using local caregivers was highlighted by Mohammad and Gikonyo (2005, p. 13), namely that the caregivers “are then more likely to experience stigma, discrimination and social isolation due to the nature of their work.” Hence, because the community knows what work the caregivers are doing and who they are visiting, and because the volunteer lives in the same community, it makes them vulnerable to stigmatization. **Maria** felt strongly that community support was not that evident saying:

> *The family members are ... too worried about what the neighbours are saying. You’re talking about community care. Most of the people with AIDS don’t even want other people to know their relatives have got it.... So our stigma and discrimination is still very rife in many of the communities in which case that patient is more likely to be hidden than [receive] all this support*

The situation whereby individuals in communities, due to community pressure, do not seek assistance for their condition leading a worsening of their health and could be regarded as negative social capital.

Thus, communities are very influential. While stigmatization can be problematic, conversely, having the community's support inspires the caregivers to keep going as caregivers as it gives an added sense of meaning to their work. Akintola's study (2010), "Perceptions of rewards among VCGs of people living with AIDS working in faith-based organisations in South Africa", a qualitative study, demonstrates that VCGs value the support of community members highly.

In terms of social capital, according to Kawachi (2006, p. 992), "at the community level, social cohesion may be a reflection of the health status of residents (i.e. you have to be healthy to volunteer)." Based on this statement, it is possible that where VCGs received support from their communities, that this social cohesion could positively affect their clients, thus leading to improved quality care.

In short, communities can enable caregivers to find caring work and can also play an important part in supporting these caregivers. While this support can improve the quality of care, negative community involvement can be destructive to caregivers. Thus it is crucial that communities encourage caregivers as they are extremely influential. The positive effects of this power are evident in the impact that community involvement has on social capital, which in turn may also improve quality care.

5.4 Theme 3: Addressing structural challenges to improve the quality of CHBC

This theme focuses on the structural challenges facing CHBC organisations and how to overcome them in order to improve the quality of CHBC. First, in the sub-theme on the challenges of training of VCGs, the personality attributes of prospective VCGs that CHBC organisations should look for are discussed. In addition, under this sub-theme, improving training via standardisation and training volunteers to have multiple skills is also discussed. The next sub-theme, on challenges related to monitoring and evaluation, covers the government's role in monitoring and evaluation, the current reliability of monitoring and evaluation in CHBC and the role of mentoring and supervision in CHBC. The third sub-theme is that of developing a scope of practice and the importance of developing parameters and legal boundaries.

5.4.1 Training of volunteer caregivers

Various aspects of training pose a challenge to CHBC organisations: First, a discussion of the challenge of selecting caregivers with the appropriate personality attributes for providing quality care is presented. Second, an investigation of how to improve training through standardisation is discussed. Third, the challenge of training volunteers to have multiple skills is presented.

- **Personality attributes needed by volunteers to provide quality care**

It is vital that organisations ensure that they are using volunteers who have the right attributes to be good carers. There were several personality attributes that were repeatedly mentioned by both the key informants and the supervisors, namely: compassion, maturity and confidentiality, physical characteristics, and intellectual ability so that volunteers are able to be trained in certain skills. These attributes, which are discussed below, were also highlighted as important elements of quality care by the Republic of Namibia’s Ministry of Health and Social Services’ *Community-Based Health Care Policy* (2007). If these skills are developed, they in turn will increase human capital, an aspect of social capital, which will benefit CHBC organisations.

CHBC organisations need to make sure that the volunteers they recruit have the right personality attributes. This is supported by **Lucy**, who argues,

> *So, if you’re looking for quality it is also the work that needs to be done by the institution or the organisation in terms of having a proven policy what it is that you are looking for within that person before you bring them on board as a caregiver.*

She felt that even before the caregivers receive their training the organisations need to screen them to ensure that the right people are selected. She admitted that it was a difficult task, because people could come out of desperation and “give you what you want to hear.” **Ruth** notes that there are specific attributes required by a VCG to provide quality care:

> *Personality plays a big role because it is very taxing on the individual emotionally, physically, mentally, psychologically – you actually have to be [a] strong person because they cope with a hell of a lot out there. Personality plays a huge role and their emotional stability, they really are left out there to cope with a lot of stuff on their own.*

One of these attributes is compassion. This was noted by **Lucy**, who stated: *"The word comes back to compassion, having the compassion for the work."* **Maria** supported this too and felt that compassion was vital for quality care: *"When you come to quality in HBC, you can have all the skills in world, but without the compassion for the families, for the clients, for the patients, the quality won't be there."* Supervisors too emphasized the importance of compassion. For example, the characteristics that they felt CHBC volunteers required were that they needed to be/have:

- *caring*
- *Caring knowledge or experience*
- *someone who have love unconditionally.*

The Republic of Namibia's Ministry of Health and Social Services (2007) also referred to the vital importance of compassion for quality care, referring to "compassionate relations" (p. 43) as an important dimension of quality.

Another attribute that was highlighted was maturity, which was linked to confidentiality. One of the supervisors said that a requirement for a VCG was that he or she be "matured.*"* **Gladys** felt that *"A quality caregiver should be a person who is emotionally mature. And also mature enough to be confidential…."* Therefore, she felt that age played a role and she suggested the caregiver be above 20 years. **Ruth** did not specify the age of VCGs, but suggested that it should be considered. **Beulah** noted that there was a lot of stigma and discrimination around as well, and sometimes it was a caregiver who knew what was happening in the household of a client who spread gossip about the family. So according to her there was an issue of confidentiality amongst the caregivers. Additional characteristics that the supervisors felt CHBC volunteers required were that they:

- *[be] matured*
- *Must have confidentiality*

The Republic of Namibia’s Ministry of Health and Social Services (2007, p. 45) stated under their “Specific quality guidelines” that confidentiality be kept and that volunteers must be mature people, thus supporting the statements from the interviewees and supervisors above.

A third important element that was noted was the physical attributes of the volunteers. According to **Ruth** *“...sometimes they are not able to carry out some of the stuff. . . . size, weight and also culturally….”* Age is tied to emotional maturity and size and weight is directly related to the physical side of caring. A person who is too small or overweight may find it difficult to do physical care work. **Ruth** said: *“...we have carers who we know are not going to cope with physical work….”* One of the supervisors also highlighted the importance of the volunteers being *“physically fit”.* The Republic of Namibia’s Ministry of Health and Social Services stated that volunteers may be expected to: “assist with cooking, fetching wood, water, domestic chores, cleaning, child care, according to the prevailing situation” (2007, p. 45). All these activities listed require varying degrees of physical strength. An inability to perform certain acts of physical care will impact negatively on the quality of care.

A further important requirement was the trainability of volunteers or their ability to acquire certain skills. According to **Ruth**, *“They got to be intellectual enough to be able to upgrade and to keep learning not just go and do….”* The supervisors also emphasised the importance of volunteers having the necessary training to do the care required of them:

- *HBC course and experience; experience in working with communities affected/infected with HIV and AIDS; basic counselling skills.*
- *must have skills (e.g.) HBC; HIV training skills*
- *experience in working with communities affected/infected with HIV and AIDS; basic counselling skills.*
- *must be trained on 59-days; must get basic training;*

The Republic of Namibia's Ministry of Health and Social Services (2007) also highlights the importance of trainability noting that volunteers must be "able and willing" (p. 45). The personal criteria required by VCGs to provide quality care are closely tied to the concept of human capital. The inherent abilities and values that reside in each volunteer will directly affect the care that they provide to their clients. However, it is the development of these personal traits through training that will increase the human capital of each volunteer. Coleman expresses this as follows: "…human capital is created by changes in persons that bring about skills and capabilities that make them able to act in new ways" (Coleman, 1988, p. S100). The increased human capital will then impact on the collective efforts of the volunteers and present itself as increased social capital, benefitting the community as a whole.

To conclude, organisations need to be sure that they are selecting volunteers who have the attributes to become effective carers. Personality attributes that have been identified as promoting quality care are compassion, maturity and confidentiality, physical characteristics, and intellectual ability so that volunteers are able to be trained effectively in certain skills. If these skills are fostered, they will cause the growth of human capital, which will positively impact on the social capital of CHBC organisations.

- **The relationship between volunteers' education levels and training**

In the previous section, trainability was indicated as an important personality attribute. Closely tied to this attribute are the educational levels of the volunteers, which determine whether they are able to cope with CHBC provision and training. Some of the VCGs did not have the necessary levels of education to enable them to manage the training provided, although overall education levels of the participants were fairly good. This was in contrast to general findings of the literature that emphasize the low educational levels of caregivers, but although the participants in the study may have higher levels of education, the quality of this education is difficult to ascertain. Lack of education/poor quality education can mean that caregivers struggle to cope with their work. Thereafter, a possible solution is proposed. This solution is followed by a discussion of the relationship between education levels, training and quality care and thereafter the relationship between education levels, training and social capital.

As is evident from the following statistics some of the VCGs do not have the appropriate educational levels for providing adequate CHBC although their overall education is relatively high. Twenty-one of the caregivers were in the category Grade 10 – Grade 12 and five were in the category Grade 8 – Grade 10. Four were in the category Grade 4 – Grade 7 and one was in the category Grade 0 – Grade 3. One caregiver did not indicate his highest level of education. Based on these statistics it appears that most of the caregivers in this sample have a reasonable level of literacy. Of the 32 caregivers, 81.25 per cent had a secondary school qualification. This is important, especially regarding the monitoring process, which requires the caregivers to provide basic information about their clients and the number of visits undertaken each month. It is also a factor that influences the caregiver’s ability to take part in training and fully understand the course content. It is reassuring to know that 65.63 per cent of the caregivers had a school qualification of at least Grade 10, as a minimum of *Standard 8* (Grade 10) was indicated as a selection criterion by two supervisors.

These relatively high levels of education are in contrast with the generally poor education of caregivers. Overall, there appears to be an overall problem of a lack of education amongst VCGs (Mohammad & Gikonyo, 2005; Lindsey et al., 2003). Lindsey et al. conducted a study in Botswana of young girls and women caregivers and noted: “…these caregivers experienced poverty, social isolation, stigma, psychological distress, and a lack of basic caregiving education” (Lindsey et al., 2003, p. 486-487). The final stress factor was “a lack of basic caregiving education”, which is evidently a problem amongst volunteer and family caregivers. Furthermore, a study by Phorano, Nthomang and Ngwenya (2005, p. 167) indicates that with “respect to education, the study revealed that a higher proportion of respondents (28, or 32.9%) had lower primary education, while 20 (23.5%) had higher primary, 19 (22.4%) a junior certificate, 7 (8.23%) non-formal education, 3 (3.53%) had Cambridge certificate and 8 (9.4%) had never attended school” and they indicated that poor education levels could impact on the caregivers’ ability to provide quality care.

However, despite the fact that the participants in the current study appear to have higher than average levels of education, it is also important to bear in mind that many of these caregivers received their education in township schools, many of which are under-resourced and with teachers who often only have Grade 12 themselves. This means that some of the Grade 10 – Grade 12 education levels may not be of the standard that they should be. Organisations that provide training must bear this in mind and accommodate the caregivers by first ascertaining "where they are at" and then providing them with training that meets them at their current level and builds them up from there.

Poor levels and quality of education can negatively impact on caregivers' ability to do their work. **Belinda** (FG2) spoke of the literacy and education of the caregivers being at different levels, while **Janet** (FG2) felt that the VCGs needed the correct education so that they feel empowered to do their work. **Belinda** (FG2) said that in training you may think you have given them the information and that they all understand, but they do not. This was supported by **Alice's** (FG2) remark that they all say "yes", but when you get the results you can see they do not understand. She suggested grouping the caregivers with the same education levels and setting the curriculum to suit them. **Sarah** (FG1) said: *"I say this with great love for our volunteers, we are working with volunteers who haven't had the same advantages of education as maybe others of us have."* Regarding the selection of participants to undergo training at their organisation, **Ruth** said:

> *...even though we have guidelines of what the requirements are we do find that sometimes the selection is not good—level of education.*

A possible solution is to make training simpler and more practical and for it to be provided in the home language of the caregiver. **Beulah** spoke of a medical doctor in Hamburg (Eastern Cape) who had developed training materials for caregivers that were very practical, involving art, creative drawing, poetry and very simple words to communicate. Her methods were very interactive and she was able to simplify all the complicated medical terms, especially regarding HIV and AIDS in order to make them accessible to the caregivers who often have very low levels of education**.** According to **Beulah**, there was an enthusiastic response from the participants in this doctor's workshop: *"Everybody walked up and said, 'I have been empowered. I never understood this virus, like, I now know it. And if I know it, I can educate others."* In support of using a practical approach **Belinda** (FG2) argued: *"And the practical. A lot of practical... If you are doing first aid today, whatever, then they must demonstrate what they understood. That's how I learnt it— every day."* **Rebecca** also indicated:

"One of the other weaknesses is practical experience." However, she said during advanced HBC training *"…we do have a week practical where we ask the hospitals or the old age homes to allow our participants to practise for a week at least."* **Gladys** was critical of the well-known 59-day training course:

> *But what made it 59? Because some of the people they are not educationally empowered generally speaking. Ja, perhaps 59 days is what, two months. If it could have been 59-day course, practicals, you know, somewhere in between there's the practical aspect, practical applications.*

Peltzer, Tabane, Matseke and Simbayi (2010), note that it is also possible that effective training can take place over a short period of time. For instance in their study, the "training of the lay counsellors in [their intervention programme] took a relatively short time (3 days) [which could] be readily integrated into ongoing lay counsellor trainings" (Peltzer et al., 2010, p. 384).

While an appropriate level of training for caregivers is obviously necessary, it seems that there is a distinct gap between theory and practice and there is an urgent need to ensure that what is taught can be implemented in their work with clients. The literature supports the need for practical training with Nzimakwe and Xaba (2008, p. 138) stating that: "The caregivers are taught both theory and practice. They therefore need correlation of theory and practice, which has to take place in practical sites. Practical sites need to be identified in the community where the caregivers can actually put into practice what they have learnt in the classroom." Also regarding training methods, **Estelle** (FG2) felt that language was important, because training tended to always be in English, and she felt that there needed to be some isiXhosa.

The quality of training that the VCGs receive has a direct bearing on the quality of care that the clients receive. Furthermore, if the caregiver is not suitable from an educational perspective, this will also have an impact on the quality of care that he or she is able to provide. Low levels of education make it difficult for VCGs to "follow the hygiene protocol in the care process or [to provide] quality care" (Kang'ethe, 2009, pp. 28-29). However, if some volunteers have not had access to education and training they "should have the chance to be educated and trained in another way. HIV- and AIDS-related education and training can be provided at home for individual patients as well as for the family" (Senaratana, Nantachaipan & Potjanamart, n.d., p. 360).

In the context of training, there are three main role players, namely the trainers, VCGs and the clients. The trainers are able to transfer knowledge to the VCGs as they are from a higher educational level, and the relationship between the trainer and volunteer consists of bridging social ties. According to Szreter and Woolcock (2004, p. 655), "bridging social capital . . . comprises relations of respect and mutuality between people who know that they are not alike in some socio-demographic (or social identity) sense (differing by age, ethnic group, class, etc)." In the case of this study, the difference between the trainer and the volunteer, and the volunteer and the client, is not necessarily ethnic group or class but rather educational. Hence, the transferring of knowledge and skills from trainer to caregiver and then again from caregiver to client contributes to the overall quality of the care continuum, because the caregivers and clients are better equipped to deal with various lower level health care issues and are able know when to refer.

Thus, trainability and educational levels are crucial if VCGs are to manage CHBC provision and training. Some of the VCGs in the current study lacked the required educational levels to cope with training although overall education levels of the participants were reasonable. This finding contrasts with generally low educational levels of caregivers, but although the participants in the study may have higher levels of education, it is possible that the quality of their education was poor. Inadequate or poor education can result in caregivers' not coping with their work. A possible solution is training that is very practical and in the language of the trainees. A benefit of such training, if it is effective, could lead to better quality care and improved social capital.

- **Improving training through standardisation**

In this section, the need for standardisation of training is highlighted and thus the need for a standardised CHBC training course. However, this standardisation is reliant on government support, which in turn could lead to an increase in quality of care and a strengthening of social capital.

First, training needs to be standardised, which was emphasised by **Lucy** who stated: *"And I actually say amen to the standard—that there should be a standardized programme for all carers."* **Maria** also elaborated on the need for standardisation in order to prevent academies that make money from training by luring people with promises of non-existent jobs and claiming that it would *"increase the quality [of care]."* **Sarah** also felt strongly that standardisation was necessary, saying *"I truly 120 per cent agree with standardisation and accountability."*

Furthermore, in order to standardise training, a standardised CHBC training course needs to be developed. For example, **Mabel** spoke about the need for a core structure or training programme that all volunteers need to complete and she envisioned it to be in the form of a learnership. She argued that *"whether you are going to go into the care of the elderly, or of children or of the terminally ill there needs to be a core structure that every careworker needs to complete."* There are a range of different types of training taking place, as discussed by Schneider and Russel (2000, p.17):

> There was little standardisation across projects with regard to training and the quality of services provided. Some programmes sent their volunteers and staff to formally established training programmes, while others conducted their own in-house training. Hence, the content and quality of care varied enormously.

This is affirmed in more recent research on CHBC training by Thabethe (2006). Thabethe, when researching the training manuals from four CHBC organisations, noted that "having reviewed the different manuals, it was clear that the training in CHBC does not provide a standardized format. The content and duration of the courses vary considerably" (p. 32).

In order for standardisation of training to occur there needs to be strong support from government as this will improve the quality of care. **Mabel** emphasized the need for the government to be involved in the improvement of training, noting that it is those in government who *"have the structures to deal with it."* The government also needs to provide financial support to training efforts as costs of training are a concern: As

Beulah mentioned, *"I'd love for everybody to be properly trained, but it's an expensive exercise."* This is why the need for government funding to improve the standards of training and therefore the standards of CHBC is necessary.

This government intervention can have a positive effect on the quality of care being provided. For instance, Boros (2010), who supported the need for government financing, indicated how this would benefit the overall quality of CHBC in terms of comprehensive care and standardisation:

> With a relatively minimal increase in funding (mostly for added training costs), the DoH could drastically improve their reach and coverage, providing a more comprehensive service to PLHIV [people living with HIV or AIDS] and others. At the same time, the formal health sector could be confident that the care being provided by all HBC organisations meets minimum standards (Boros, 2010, p. 322).

The DoH (2001) *National Guideline on Home-Based Care / Community-Based Care* places a strong emphasis on training, even identifying it as the second of the three pillars of HBC and community-based care. However, it is unclear who is to take responsibility to provide the training. As such, there is no provision for the standardisation of the training as there is no driver indicated for this important task. Hence, it is argued that government should play this role. Mohammad and Gikonyo (2005) support this argument when referring to quality care saying that there is a need for "a nationally recognized training program for volunteers, which allows them to be certified in community home-based care, with the possibility of further training for placement within the health care system." (p. 21)

Standardisation of training is closely linked to structural social capital which, according to Uphoff (2000) consists of "roles, rules, precedents, and procedures" (p. 218). Standardisation of CHBC training would fall under "rules" and "procedures" and actually assists in increasing social capital by increasing the "mutually beneficial collective action" among caregivers themselves and between volunteers and their clients.

To sum up, standardisation of training is important and for this to happen, a standardised national CHBC course is necessary. A further requirement for this to become a reality is government support. Positive results of government intervention in this matter would be better quality of care and social capital.

- **Training volunteers to have multiple skills**

It is clear from the emphasis on the trainability and skills that caregivers need (cf. section on personality attributes) and the value of holistic care (cf. section on counselling and holistic care) that it is important for caregivers to be multi-skilled and the importance of this is discussed below. Thereafter, follows an analysis of the extent to which VCGs in this study are skilled in the fields of CHBC training, HIV education training, First Aid training, tuberculosis (TB) training and training in the care of orphans and vulnerable children (OVCs). Having such a range of skills is necessary to ensure quality care. Thus, the solution is to train VCGs in a variety of fields so that they are multi-skilled, and subsequently they will also need refresher courses. This training will in turn increase the human capital of the volunteers.

First, being multi-skilled is an essential element of an effective caregiver. This is clear from the DoH Guideline (2001), which states that CHBC is meant to be holistic, encompassing “physical, social, emotional, economic and spiritual” (p. 4) factors. To provide care in all these facets, volunteers need to be equipped to have multiple skills. Five of the CHBC programme managers also spoke about the importance of being multi-skilled. In addition, **Sophia** also mentioned this aspect of care, saying that she felt that VCGs were multi-skilled and were able to provide holistic care (body, mind and soul) to the client.

However, not all the caregivers in the current research project had an adequate range of skills. Of the 32 caregivers, 81 per cent had received training in CHBC. However, five caregivers (16%) had not received CHBC training, and yet they were engaged in CHBC work. The question is whether or not they should be allowed to be doing care work. Of course they may have received in-service training. However, the DoH needs to maintain strict controls on who may or may not practice as a CHBC caregiver so that the clients who are on the receiving end of the care are indeed receiving quality care from qualified individuals.

An area in which most of the participants had received training was HIV education. According to the findings, 94 per cent of the caregivers had received training in HIV education. This is very encouraging, bearing in mind the strong emphasis that the United Nations (UN) places on the role of care and treatment in the process of HIV care and prevention (UNAIDS, 2005b, p. 4).

The number of caregivers that had not completed First Aid training was quite high, with nine caregivers (28%) not having had First Aid training. First Aid training is important as it forms a solid grounding for the VCG with regard to health care emergencies that occur in the household. It is important for their formation as it helps them to be an all-round caregiver and gives them the confidence of knowing how to respond when confronted with an emergency.

The main standout point is that only half of the caregivers had received TB training. Fifteen (47%) had not received TB training, which means that they are not multi-skilled with regard to HIV and TB. It is important that the caregivers receive training on these two diseases, because they are so closely interrelated and because they are so entrenched in the communities in which the caregivers live and work.

Care work almost always involves caring for children as well, and it is interesting to note that only 53 per cent of the caregivers had received OVC training. The care that children require generally involves counselling of a different kind. Orphan children are one of the most vulnerable groups in society and their care requires deep compassion, but also the necessary counselling tools to have a positive influence on the child’s life. CHBC organisation managers need to be sure that those caregivers who are dealing with children have the necessary skills to care for them.

It is essential, for the sake of quality care, for caregivers to have training in many different aspects of CHBC. This was highlighted by **Rebecca,** who noted how a holistic approach to caregiving would result in the caregiver having the knowledge and education to know what is quality CHBC:

> *[Using an integrated system] the caregiver will have the knowledge and education to know that [the care he or she gives] is quality, the person receiving it will know that this is what I should be getting, this is quality, this is how it should be and the family would say that this caregiver shouldn't be doing things like this, so you would have everybody being aware of what is what.*

The need for VCGs to have multiple skills was emphasised by Colton, Dillow, Hainsworth, Israel and Kane (2006) who listed the following skills as important for CHBC: "positive living, self-care, nutrition, hygiene, prevention of STIs (sexually transmitted infections), contraception, emotional support, and basic nursing care of bedridden clients" (p. 90). The specific quality standards for HBC, in the Namibian *National Policy on Community-Based Health Care* also identified other activities expected of volunteers, namely, how to access social grants and when to refer social workers (Republic of Namibia's Ministry of Health and Social Services, 2007).

The way forward for CHBC would be to equip the caregivers to provide holistic care. **Rebecca** agreed and indicated that in her case one of the benefits of CHBC was that the VCGs were trained in the skills to care for sick people and so were also able to train the families of these sick people to care for their family members. Of course this is in an ideal situation where all VCGs are equally skilled. **Lucy** felt strongly that besides physical care the volunteers needed to be well-equipped to provide their clients with counselling:

> *I will not trust someone who just has the nursing background, but they don't have the social background ... you can bring all the education in terms of how to do VCT [voluntary counselling and testing], how to [do] whatever is needed, but do you teach that person or train that person how to do the counselling as well? You cannot do the one without the other. So we speak quality. You need to be able to do the counselling as well as go the VCT route.*

As mentioned in Chapter 3, VCT has been replaced by HIV counselling and testing (HCT) (Skinner, 2010). The training provided by Organisation A in this study seeks to provide holistic training to the volunteers whom they train. According to this organisation, *"we . . . go beyond HBC and First Aid, we've given them community development training, because we want them to have a better understanding of the community and how to assess the needs of the community."* Organisation A emphasised the importance of training and the need for the volunteers to build on it: *"The idea is for them to actually get the skills and build on it as they go along."* **Mabel** too supported the idea of diversifying the skills of VCGs, saying that *"[A caregiver is] almost like a nursing auxiliary. Let's diversify their ability to be utilised in the community."* **Gladys** believed that VCGs should be multi-skilled and that they should be made Directly Observed Treatment, Short Course (DOTS) (TB) supporters in addition to being AIDS VCGs. She said that some of them had been trained in First Aid as well. From a clinic perspective **Maria** said that having caregivers who were only trained to care for PLHAs did not help. If such a caregiver was working in a particular area and the three or four streets that were allocated to her had a mixture of TB and HIV patients who attended the clinic, she would only visit the HIV patients. Therefore, **Maria** felt that caregivers should be trained in both HIV and TB. She also highlighted the fact that most of HIV patients had TB and that the TB patients were HIV-positive so having caregivers trained in both actually worked better. As discussed in the previous section, government support is essential to ensure that this training is standardised.

Furthermore, refresher courses would be valuable in maintaining and increasing what caregivers learned in multi-skilled training. The participants mentioned refresher courses, which are really essential if the volunteers wish to keep in touch with the skills with which they have been equipped. **Ruth** said: *"... [the refresher course is] not something that we just publicly offer. [Some agencies request it to] . . . just see that [the volunteers are] on the right track."* The need to undergo refresher courses was highlighted by **Ruth**:

> *I would say [the refresher course] should be every five years ... because we've actually done a refresher course with a group from an old age home who had been trained more than five, ten years ago and it was quite shocking to see what they had forgotten.*

However, the refresher course is not like the First Aid course which has to be taken every three years. She said:

> *If they are in the field they are obviously doing it all the time, working with the patients. But if they did the training today and two years later they come back and just do a refresher… [that] we do often.*

The Namibian *National Policy on Community-Based Health Care* also stated that for quality care to take place “continuous and regular supportive supervision and refresher training will be conducted” (Republic of Namibia’s Ministry of Health and Social Services, 2007). Furthermore, in a Botswana study the need for refresher courses was identified by a participant and it was noted that clinics provided volunteers with refresher courses “when the need arose” (Morna et al., 2009, p. 15).

The training aspect of CHBC volunteers falls under human capital: as Erickson (2001, p. 139) states, “Human capital includes both education and work experience.” Volunteers are taught knowledge and skills which equip them to undertake the role of the caregiver. As the volunteers acquire new knowledge and skills, the social capital that exists amongst the caregivers and between the caregivers and their clients will increase. Knowledge and skills are transferable (or fungible) and when these are transferred from the caregivers to the clients, the human capital of each client is increased. Indeed, as emphasised by Woolcock (2001), it is the relationships between people that are all important, as despite a person, such as a VCG, being well-trained, he or she needs others “to inform, correct, improve and disseminate his or her work” (p.69). He describes how human capital and social capital complement each other: “Human and social capital are complements, however, in that literate and informed citizens are better able to organize, evaluate conflicting information and express their views in constructive ways.” (p.69)

In conclusion, it was shown that some participants in this research study lacked skills needed for CHBC. The fields of CHBC training, HIV education training, First Aid training, TB training and OVC training were investigated. Because having such skills is important for the sake of quality care, it is important to train VCGs to be multi-skilled and to ensure that refresher courses are made available. This training will in turn increase human capital, which in turn will result in a growth of social capital.

5.4.2 Monitoring and evaluation

It was found that there is a great need for monitoring and evaluation, which helps to prevent the occurrence of certain problems affecting the quality of CHBC received by the client. The following areas will be examined under this sub-theme: the government's role in monitoring and evaluation; current reliability of monitoring and evaluation in CHBC and the role of supervision and mentoring in CHBC.

- **Government's role in monitoring and evaluation**

The findings for the current research project have indicated a need for greater monitoring and evaluation. A solution to this problem is increased involvement from the government. While the government has set out and undertaken the implementation of countrywide monitoring and evaluation, it is debatable whether all CHBC organisations are receiving adequate, if any, support. Effective monitoring and evaluation are required in order for quality care to take place and to strengthen social capital.

There appears to be insufficient monitoring and evaluation taking place in some organisations. The problem with a lack of monitoring and evaluation was raised by **Rebecca**, who said, *"We do the training, but there's nobody out there to monitor them, to follow up."* She later stated: *"But if [a] ... CBO has just opened, and they are doing this work on their own there's no monitoring really; they are going to just do it however they feel."* Jansen van Rensburg (2009) warned that in cases like this monitoring and evaluation is critical: "It is crucial to have systems in place from the initiation of a project. Continuous monitoring and regular evaluation of the process, outcomes, and impact are essential" (p. 25). **Lucy** too felt strongly that there was a lack of monitoring and evaluation:

> *Even with the Department of Social Development [DSD] with your various NGOs, because they will cry in meetings about the same things—I'm speaking about the department itself. And you'll immediately know that it's because … of a lack of M&E [monitoring and evaluation].*

She went on to say that if monitoring were taking place, there would be far fewer problems than at present.

A solution to remedy this is greater government involvement. While there are different types of monitoring (there is the micro-level monitoring and evaluation which takes place at CHBC programme level and there is broader monitoring and evaluation that take place at meso- and macro-levels). Boros (2010, p. 323) argued that "Priority should be given to monitoring and evaluation for the HBC programme." He said that "This would include monitoring the quality of care provided by HBC organisations, but equally important it could involve monitoring the relationship between clinics and these organisations" (2010, p. 323). This kind of meso-evaluation can only be undertaken by government as the coordinator of CHBC. His opinion in favour of government involvement was shared by **Gladys**, a high profile figure in the municipal health sector. She felt that the government needed to play a bigger role in the monitoring and evaluation of CHBC programmes. She stated that *"government need to design monitoring and evaluation mechanisms because the home-based care system is not being evaluated. I have not heard of anybody doing a study in evaluating home-based care."* **Rebecca** too felt that the government's involvement is important and she recommended that the government works with CHBC organisations: *"If you talk about monitoring, I think that the DoH should establish some kind of a relationship with [CBOs]."* It is not only the key informants, but also the South African Constitution that indicates that government needs to be involved with regard to the monitoring of norms and standards:

> According to the Constitution (1996), welfare services are the joint responsibility of national and provincial governments. The National Department is responsible for the development, implementation and monitoring of norms and standards, while the provincial departments are

> responsible for the planning, development and delivery of services. (Adams, Claassens, Dikweni & Streak, 2001, p. 10)

The government has made some positive steps towards increasing monitoring and evaluation. The DSD's (2010) *Strategic Plan 2010-2015*, illustrates the government's commitment, in theory, at least, to monitoring and evaluation. According to the *Strategic Plan* (2010), "one of the key developments in respect of HIV/AIDS is the development and expansion of an integrated Monitoring and Evaluation system for home and community-based care at all levels of governance and service delivery in the country" (DSD, 2010, p. 54). This monitoring and evaluation system, according to the Strategic Plan, is presently taking place as a joint operation between the DSD and the DoH, using the financial and technical help provided by the Japanese International Co-operation Agency (DSD, 2010). **Maria** was concerned, though, that the practice of government monitoring and evaluation does not match the theoretical commitment of the department. For instance, she said that staff needed to do personal check-ups on caregivers in the form of spot checks so as to observe the care being provided to the client.

> *But your supervision and monitoring from a clinic/government side is just not there. I'm sorry, I dispute it if they try and tell me that. There's not one sister that's getting into a car and spot-checking any house to say: "How is it going?", so nothing is verified, so I mean, I can write whatever I want.*

Thus, it appears that, despite the government's responsibility being enshrined in the South African Constitution, most of the care organisations in this study have not received the government's support regarding the monitoring and evaluation that they needed. For instance, Boros (2010) noted that although many HBC organisations do receive sponsorship from the DoH, "a larger number operate with no government funding or support… they are largely unregulated and unmonitored — their caregivers receive less training and their activities and contributions go largely unrecorded" (p. 322). **Rebecca** said that because the DoH and DSD provided a lot of funding to CBOs therefore they should put a lot more emphasis on monitoring and evaluation, but according to her, they did not. Hence, the implication is that the government provides funding to CBOs and then they take it away when the CBO does not perform, thus leaving the CBO to go searching for other funding.

Proper monitoring and evaluation is essential for quality care. For instance, the Zimbabwe government has noted the importance of monitoring and evaluation in providing effective care, arguing that “uniform guidelines or standards” (Ministry of Health and Child Welfare, Government of Zimbabwe, 2004, p. 3) enable effective service delivery. However, the lack of countrywide monitoring and evaluation systems for HBC in Zimbabwe “has limited the capacity of HBC programmes to identify and disseminate best practices for replicating and sharing lessons learned” (Ministry of Health and Child Welfare, Government of Zimbabwe, 2004, p. 3). South Africa’s DSD (2010) also acknowledges the importance of government involvement in monitoring and evaluation, because it will increase quality care. Furthermore, Family Health International (2004, p. 12) states that: “Regular monitoring and evaluation of the efficiency and effectiveness of the comprehensive care continuum is thus crucial to ensure that the client is able to maintain some level of quality of life.” And this quality of life is a direct result of quality care.

In terms of social capital, structural social capital includes roles, rules, precedents and procedures (Uphoff, 2000). Monitoring and evaluation falls under this aspect of social capital. If the government is to play a role in strengthening social capital in disadvantaged areas such as townships, it will need to lend its assistance to establishing the necessary structures to ensure that CHBC is monitored and evaluated effectively. Another aspect of social capital is the need for bridging social ties. Government expertise in the field of monitoring and evaluation when shared with communities and community organisations will result in bridging social ties, leading to a transfer of knowledge and human capital, thus providing greater social capital in such communities.

Thus, increased monitoring and evaluation appear necessary, and a key solution suggested was greater government involvement. While the government has taken some steps towards expanding monitoring and evaluation, additional government support is needed. Furthermore, comprehensive monitoring and evaluation are required in order for quality care to take place and to strengthen social capital.

- **Current reliability of monitoring and evaluation in CHBC**

While government monitoring and evaluation are important, monitoring and evaluation by those who are not in government is also essential, and most of the caregivers in this research project indicated fairly recent monitoring, which they termed "evaluation." However, a drawback of monitoring and evaluation is that caregivers do not always understand the monitoring/evaluation systems, even after these are explained. Another weakness of current non-profit organisation (NPO) monitoring and evaluation is dishonesty by caregivers. One solution to these problems is the development of indicators, but these may also be misunderstood. A more viable solution may be fostering a closer relationship between supervisor and caregiver, and it is also important that government play a greater role. It is important that solutions are implemented as reliable monitoring and evaluation is vital for quality care and also improves social capital.

Most of the caregivers had undergone monitoring and evaluation by their respective NGOs quite recently at the time of the interviews. On average, caregivers said that they were last evaluated two months before the time of their interview. One said she was last evaluated a year before the interview and two said they were last evaluated a week before the interview. It seems that most of the caregivers consider evaluation to be a form of monitoring. The caregivers stated that the monitoring was conducted either by their supervisor (59%), the management of their CBO (25%), or a donor (3%). The majority of caregivers (81%) said that they also received feedback from the person who did the evaluation. This is very positive, because it indicates that the purpose of the evaluation was to help the caregivers to improve their care work and not simply to check up on them.

A problem with monitoring and evaluation, which often involves completing forms for statistical purposes, is that systems are not always understood. **Gladys**, for example, said: *"I won't say home-based carers are not truthful. . . . But some of them are not educationally empowered."* A caregiver will often fill in data that are linked to the frequency of visits to a particular client, which can lead to confusion, as indicated by **Sarah**:

> *When you have a [question] 'how many children did you visit this month?' and so they'll put three, and then this month how many children did you visit this month, and they'll put three. Now we don't know is it the same three you put last month or...so you add up at the end of the year, and you've got 2600 children, and you know, is it 2600 children, or is it 3?!*

Furthermore, explaining how the statistics forms work is often challenging. **Sarah** stated that *"They're not necessarily understanding the stats form even though you explain it 10, 000 times in 10, 000 different languages, so that they understand, but the stats, we have them because our funders require them."* Hence, it is often the funders that push strongly for very rigid, poorly understood monitoring processes with an emphasis on quantifying every care act. This rigid structure is generally linked to financial concerns. For instance, **Rachel** explained that funders from the UK wanted to make sure that monitoring was taking place *"to ensure that money is not being wasted."* In addition, **Rachel** said that one of the jobs of Organisation A is to assist NPOs to apply for funding and part of this includes helping them to undertake monitoring of their organisation.

Another weakness of the monitoring process is that it can encourage dishonesty. **Maria** spoke about the forms that caregivers filled in so that the clinic or NGO could keep track of how many clients were visited and what services were being provided. She commented that

> *Everybody knows everybody in the street so they know who they can put down [on the stats form], but that doesn't mean that they really did bed bath a patient. That doesn't mean that they took food to the patient or did anything you know. So there's a lot of talk that goes with it.*

Lucy too has experienced this and said that at her organisation they tried to counteract this by cross-placing people so that they did not have volunteers living within the same area, but the expenses for bus fare and so on prevented them from continuing with it. **Maria** supported the idea in principle, because it would force the caregivers to actually visit the house of a client in order to fill in the stats forms and to obtain the client's signature. However, they could get anybody in the house to sign the form.

A possible solution to avoid unintentional inaccuracy and dishonesty is the use of indicators. For instance, in **Sarah's** hypothetical case of the caregiver who saw three children each week, an indicator would be needed to show which children were on-going clients and which were new, explained **Maria**. However, she admitted that indicators can be difficult, as some areas of CHBC are subjective, such as counselling, and thus difficult to quantify.

Another problem highlighted by **Maria** was that people generally struggle to understand the concept of indicators used in monitoring and evaluation. She noted that:

> *If you go to any monitoring and evaluation workshops with the government, you will find that half the people do not understand the indicators to begin with, so when in doubt and you have to have them handed in every month, you just make them up.*

She has experienced this frequently, stating:

> *I caught so many people out with that it was really quite annoying because it really does skew your stats. I had more people waiting for medication than had been counselled because they made up stats without checking what they were making up.*

However, greater involvement by supervisors may be a more effective solution to the problem of indicators. **Mabel** placed a great deal of emphasis on the role of the supervisor and the need for the volunteers to report back on their caregiving experiences.

> *If I am supervising you, . . . for the sake of clinical understanding and inter-disciplinary understanding you can't just give me a vague report about he said she said we did blah blah blah. There has to be times where there is a one-on-one because of the reports that are coming*

> *through and it's not about how good your English grammar is, it's about the content of what you're saying.*

For the content to be meaningful, the caregiver needs to look deeper than the superficial. For instance, if a client felt happy, said **Mabel**, the caregiver needs to consider *"what motivated that response, and what was it that you were going there for in the beginning?"* Hence, **Mabel** wished to lay the supervision aspect of volunteer caregiving not on the supervisor, nor on the volunteer, but on the relationship between the two. The conversation that takes place between the two role players brings the client to life, which is completely different to a simple statistical form, which reduces the client to a number. **Sarah** also emphasized that the supervisor could play an important role in monitoring and evaluation. For instance, her organisation places a great emphasis on monitoring and evaluation making use of a contract.

> *All the volunteers enter into a contract with us, but beyond that, every patient, the very first time a volunteer meets with a patient, the patient will have in writing, in their own home language, a contract of confidentiality and a contract of the care which they can expect. They have the contact numbers of the supervisor, and it's in writing, and it's left with them and the registered nurse. The supervisor goes through everything with the patient, introduces the volunteer, and the volunteer takes it from there, and it's just a way of keeping accountability. It's a monitoring and evaluating of the care that's going on.*

Another solution for improving monitoring and evaluation is greater government involvement. This would involve the government's assisting NPOs with the monitoring and evaluation process. The government has the ability to help re-structure the monitoring and evaluation system and also to provide funding in this regard, and this is discussed in more detail in the previous section.

Monitoring and evaluation is very beneficial in maintaining quality care, because monitoring helps to track the progress of a CHBC programme, while evaluations help to assess the changes in the community as a result of the programme (The Republic of Namibia’s Ministry of Health and Social Services, 2007, p. 41).

Indicating that expectations are an important aspect of social capital Uphoff (2000, p. 219) says the following: “Roles are created by expectations, and at the same time they create expectations, on the part both of (a) those persons who occupy (act according to) established and accepted roles, and (b) those persons with whom these role incumbents interact.” What Uphoff (2000) pointed out is that “norms, values, attitudes, and beliefs, by creating expectations about how people *should* act, by implication create expectations about how people *will* act” (p. 219). Thus, expectations are created about whether people “will be cooperative or not, whether they will be generous or ungenerous” (p. 219). Thus if expectations are carefully managed and rules and roles of a system (including monitoring and evaluation) are clearly defined and if the role players embrace the norms, values, attitudes and beliefs underpinning the CHBC operation, social capital will be strengthened.

To sum up, this section noted that reliable monitoring and evaluation is vital, and a majority of caregivers in the current research said they had experienced monitoring quite recently. Weaknesses of the monitoring and evaluation were discussed, namely that caregivers do not always understand the system or are sometimes dishonest. While developing indicators is a solution that comes with some accompanying difficulties, a more feasible solution may be developing a closer relationship between supervisor and caregiver. Government should also be more involved. If the reliability of monitoring and evaluation is increased, the result will be better quality care and social capital.

- **Role of mentoring and supervision in CHBC**

This section contains a discussion of what constitutes a “good mentor.” It presents ideas on what characteristics a “good mentor” should have. The various roles of the mentor are also highlighted. In addition, the relationship between the concept of a supervisor and mentor is discussed in the context of CHBC. Following this is a presentation on mentoring and its effect on social capital and how it impacts on quality care.

The participants in Focus Group 1 raised the issue of mentoring and the researcher then asked them: "What makes a good mentor?" **Maria** had this to say:

> *I think a good mentor is somebody that leads by example. And by leading by example ... automatically you would have the knowledge to teach, and you would have the ability to show people and you in yourself would be a good worker. So it comes down to an ethic of working, and that ethic will be passed down.*

Hence, to improve mentoring and supervision, people chosen to be mentors need to be hard-working, to have the ability to do in-service training of caregivers, to manage groups of caregivers and to lead by example. The need for mentors to lead by example was supported by **Sarah.**

Furthermore, it is important to select supervisors/mentors who have extensive knowledge and experience in community health care. **Sarah's** argument was supported by **Sophia**: *"Knowledge and experience [make a person a good mentor or supervisor]."*

Another response to the question about mentoring came from **Sarah**, who expressed the importance of mentors striving to build caring relationships with the volunteers who can be supported if they have problems:

> *I also think it's interpersonal relationship with the volunteer is incredibly important in mentoring.... We must know how are they, what's going on for them, what issues are they facing. We must be in a relationship with them so that I am approachable.*

Thus, the relationship aspect between the mentor and the caregiver is important as it is the building up of trust between them that makes the mentor approachable so that the caregiver would be more inclined to share their problems with their mentor. **Sarah** (FG 1) also raised the idea of servant-leadership saying:

> *And we believe in servant-leadership, that it's serving the volunteers in order to lead them, rather than top-down. Which can be a problem in medical care because we come from the matron approach of hospital matron care, and some of our nurses and volunteers find that a little bit difficult, but to mentor is about serving our volunteers in order to give them leadership…And inspiring the volunteers rather than demanding of the volunteers.*

The concept of servant-leadership has its origins in the Christian tradition. However, it is not an easy approach to adopt as it has the potential to be demanding on the supervisor who may be a retired professional nurse accustomed to more hierarchical systems of management. Again, there is an emphasis on the supervisor taking on the role of mentor. Furthermore, **Sarah** emphasises the importance of nurturing the relationship between the supervisor-mentor and his or her volunteers in the caregiving process. Key informant **Beulah** also stated that VCGs need continuous support and that their supervisors (mentors) are an important source of such support.

A number of points are noted, namely that there is a need for supervision in CHBC, that the project leader is a professional nurse and that the project leader plays multiple roles: manager, supervisor, teacher and mentor. VCGs need guidance and support in their care for their clients as they are not professional health care workers. For this reason, the supervisor (mentor) plays a critical role and should preferably be a professional nurse as **Beulah** stated above.

Mentoring plays a crucial role in CHBC and this was emphasized by, **Sarah**, who stated the following about mentoring: *"I think the supervision and the mentoring is a major, major, if not the most important aspect of the HBC."* **Sarah's** statement is supported by Van Dyk (2008) who argued: "Home-based care can succeed only if caregivers are well trained and if ongoing support, advice, mentoring and supervision are available" (p. 334).

Both Sarah and Van Dyk refer to supervision when discussing mentoring, as these two facets of HBC are closely linked and in the case of CHBC are often interchangeable. This is supported by Cameron (2003) who identifies the primary roles of the supervisor to be to: “nurture and mentor the caregivers, and identify and address problem areas” (Cameron, 2003, p. 36). A reason for this close link in the context of CHBC is the small size of most CHBC organisations, as illustrated in Chapter 4. CHBC organisations do not have the capacity to separate the role of supervisor and mentor, and in most cases they are the same person. Van Dyk (2008) recommends that the mentor be a person outside the hierarchy of the organisation, i.e. not having a managerial type role. However, in reality most CHBC organisations do not have a hierarchy in the strict sense of the word, because the project leader plays the role of both supervisor and mentor. This multiple role is further supported by the response of the supervisors who were asked what their role as a supervisor entailed. Two supervisors listed the following activities as part of their function, and these included mentoring:

- *Co-ordinating the two programmes – mentoring, supporting, evaluating field workers*
- *Help writing letters to donors; Home-based* **c***are; also a caregiver; guide and support and mentor caregivers; chair meetings*

Another challenge for CHBC is that, despite the importance of mentors, there appears to be a lack of mentors who provide effective mentoring. Their importance is clear as the “mentor/supervisor” is mentioned in the DoH’s *National Guideline on Home-Based Care / Community-Based Care* (2001, p. 12) as a community service provider. However, mentoring does not appear always to be happening in practice. This lack of mentoring is described by **Lucy** (FG 1):

> *I think quality also for me is mentoring. That’s one big lack that we have out there. Everybody is doing the work, I think, even from government level. You find that there are no mentors. And people flutter out there I’m sure, but they go round, and they do what they think is the right thing.*

Maria supported what **Lucy** said saying: *“It has to start from the top down first. It’s not in place. You can’t mentor them. There’s nobody to mentor them.”*

In other words, the support that volunteers need is not available and that many volunteers are undertaking their work without the professional guidance of a mentor. In

CHBC, mentoring plays an important role in the professional development of the VCGs. Regarding clinical mentorship the WHO (2005) states: “Clinical mentorship is a system of practical training and consultation that fosters ongoing professional development to yield sustainable high-quality clinical care outcomes.” (p. 8). Kang’ethe (2010b) also emphasizes the role that supervisors can play in promoting quality care, stating that their main role ought to be nurturing and mentoring the volunteers and working through problem areas with them. Doing so would “ensure that referral was done timeously, so that the quality of care would be enhanced” (Kang’ethe, 2010b, p. 554). Hence, one of the goals, and outcomes, of effective mentoring in a health care setting is high-quality care.

According to Hezlett and Gibson, in relation to social capital, of which trust is an integral part, (2007, p. 405), “facilitating trust and connection would likely contribute to the successful matching of two individuals in a mentoring relationship, whether that relationship is formal or informal.” In CHBC, the mentoring relationship takes place primarily between one supervisor and a number of VCGs. It is therefore the responsibility of the CHBC manager to promote trust between the supervisor/mentor and his or her volunteers. The higher the trust levels between mentor and volunteers, the greater will be the social capital between them and thus the clients will benefit from more effective mentoring.

In summary, caregivers need mentoring in the form of continuous support. A good mentor is one who leads by example, has a strong work ethic, has extensive knowledge and experience in community health care and has a nurturing relationship with volunteers. Unfortunately, CHBC organisations face the challenge of a shortage of mentors who can provide effective mentoring and this will have a negative effect on the quality of care. Effective mentoring is essential because it improves the quality of CHBC and the mentoring itself results in greater social capital, which leads to improved quality care.

5.4.3 Scope of practice and the need for parameters and legal boundaries

This sub-theme concerns the VCGs’ scope of practice, and stands alone without any sub-division. This section investigates the need for a scope of practice for VCGs. The first important area where this needs to be emphasised is at the training stage. Without the protection of a scope of practice, vulnerability to prosecution increases, work relationships can become tense, and caregivers are vulnerable to abuse and burnout. A suggestion to avoid such consequences was standardising a scope of practice for caregivers across the NMBM. Another recommendation was to limit volunteers' work hours. Furthermore, an effective scope of practice would succeed in increasing social capital and quality care.

There is a clear need for a scope of practice in CHBC as demonstrated by the following statement by **Maria:**

> *So I think that from this level, even at that level, scope of practice should maybe be written up that it can be adhered to and that they agree to it and sign it in, so if they're given the title home-based carer, then the home-based carer has that scope of practice, and if she goes beyond that then obviously have to be thing And the problem there's in place, the same as for nurses.*

The following quotation from Cameron, Coetzee and Ngidi (2009) supports the issue regarding the importance of some form of regulation for VCGs:

> Although they are collectively responsible for the bulk of the hands-on care provided to people sick with HIV and AIDS by home care programmes in South Africa, lay community caregivers are currently not regulated by any professional council. This means that their work has to take place without the guidelines that a mandatory scope of practice provides. (p. 102)

One area where a scope of practice needs to be implemented is with regard to the training of VCGs, which is where volunteers are formed and equipped to provide CHBC care. Therefore, it is at this crucial stage that the caregivers start to formulate an identity as VCGs, including an understanding of the range of care that they can provide. **Ruth** said that she had studied the training material of courses that were arranged to take place over three months. Due to a lack of scope of practice, some caregivers are trained in areas that should be left to nurses. For instance, **Ruth** noted that

> *Some of these three-month courses to me are trying to train them in nursing specialities which is not supported by the legal…. in other words you are training them to do things and you're putting them out in the community and if anything goes wrong they've got no legal backing.*

Ruth also said that she was concerned that some of the courses over-train volunteers *"and they think that they are then qualified nurses, they don't see themselves as HB carers and they may be overstepping the medical mark."* This argument was supported by **Beulah** who said that it was a problem, because caregivers were often under the impression that they were indeed nurses and that they entered clients' homes and claimed to be experts. **Ruth** continued:

> *…in one or two of our classes where we have had students who have done other courses and then they've told us what they've been doing in the community and as a professional nurse I get shocked to hear what some of them are doing….*

Without clear boundaries, volunteers and organisations are at risk for litigation. For instance, **Ruth** said that legally speaking if they overstepped the mark, they make themselves vulnerable to prosecution.

> *[Having caregivers in hospitals is] not a bad thing if they are restricted to their competencies, but that's what the problem is, that due to the nursing shortage they actually expect these people to do a little bit more and a little bit more and eventually they [are] actually overstepping their competencies barrier and their legal protection barriers.*

The danger of overstepping their competencies was also highlighted by **Maria**:

> *When it comes back around to ... accountability and acts of omission and legislation, so we have to go according to a scope of practice. The ladies that we're sending out into the communities, that's unlegislated. And the problem there is, ja, we don't want them to do this or that or*

> *the next thing, but what's to stop them? So somewhere along the line, we have to put some breaks in there, and unfortunately, as usual, that means a bit of paper work. I don't see that we can legislate them because it's not a legislated field.*

Sarah also emphasised the importance of legislation to protect the VCGs:

> *I think one of the big arguments, aside from money [is] what does the government need to do? Legislation is vitally important, on so many of these issues, standard of care, labour law, responsibility of organisations, because ja, organisations are easily going to get sued for things.*

Another legal reason for a scope of practice, from a CHBC organisation's point of view, is to protect the organisation from litigation. **Sarah** raised the point that care organisations could be sued. CHBC is unique in that caregivers are from the community and work in the community and may or may not have chronic illnesses themselves. It is possible that some volunteers are not aware or purposely do not reveal their HIV status to the organisation. However, if only upon working for the organisation they become aware of their status, they could accuse the organisation of not providing the caregiver with the necessary tools to protect themselves from their clients who have HIV. This issue was raised by **Lucy** (FG1), as the following demonstrates:

> *You know there is such a lot of this because if you look at them being exposed to HIV, we are just not sure when—I am speaking as an NGO—whether they have been infected already ... and when they go for testing and they are HIV-positive, it's the organisation's fault*

This is a dynamic that is not present in other working situations and that needs to be considered by both the government and the NPOs that play such an important role in CHBC. Mandatory testing, as recommended by **Maria**, may bring certain problems from a legal/human rights perspective.

Besides legal dangers, not having a scope of practice can also sour work relationships. **Rachel** described tension in the clinics between the professional staff and the clinic VCGs, where the caregivers were overstepping the medical boundary. Because there is no uniform scope of practice, some caregivers may be doing more than others, and **Rachel** said:

> *In one clinic you'll find this carer will say 'I'm doing this and this and this' and in another clinic the carer is not doing that, maybe the professional person there will say your competency ends here and there will now be a tension, because this one talks to this one.*

Maria introduced the idea of addressing the issue with the South African Nursing Council (SANC):

> *Just for clarity, what I'm suggesting is actually at South African Nursing Council level, that if we put in a subgroup of caregivers which is not there now and that we give them a scope of practice that is made legal. And to say, you cannot go past this without having repercussions. For the safety of the patients as well*

Furthermore, a scope of practice can also protect the caregiver from abusive clients or the clients' families. **Janet** explained that in some families, the caregiver is expected to do everything while the family does nothing, and noted how *"all the burden is on the caregiver, which that is not right because the caregiver is not coming to do the whole work here. She's just coming to help."* Thus the clients need to know the boundaries of the caregiver. **Janet** noted that it is family members who need to take care of other family members who are ill and *"take the responsibility."* The literature also supports the need for caregivers to be protected. For instance, Akintola (2008a) indicated how caregivers could find themselves giving in to unfair expectations if patients and patients' families have unreasonable expectations about what the volunteers should do. According to Akintola (2008a), a volunteer narrated how caregivers' roles are misunderstood: "If you don't come for one day, they threaten to report you at your work place" (p. 361). Those threatening the caregiver did not seem to understand the concept of volunteering or appreciate the hard work it involved: "You come in the morning, give them a bath and do every work in the house... and leave late in the afternoon, but they still don't appreciate it. They take it as if we are doing a paid job and that it is compulsory for us to come everyday" (Akintola, 2008a, p. 361). Such abuse can easily led to burnout. Van Dyk (2008, p. 334) noted the problem of burnout and the importance of support systems:

> One of the greatest drawbacks of home-based care is that the caregiver might give up because of exhaustion and burnout resulting from the extreme demands of caring for a terminally ill patient. It is absolutely vital for caregivers to have support systems and to know how to care for themselves, otherwise they will be overwhelmed by burnout.

A scope of practice, by providing the necessary structural support for caregivers and preventing abuse, can help to protect VCGs from burnout. **Sarah** had this to say about burnout: *"I actually spend far more time trying to get the volunteers to look after themselves and not give too much of themselves than I do disciplining any of those that maybe aren't doing what they should be doing."*

An issue that was raised was the importance of standardising a scope of practice for caregivers across the NMBM. **Rachel** said that VCGs from different clinics discussed with each other their competencies and they found out that some caregivers had greater responsibilities than others. **Ruth** felt that there needed to be a clear division between nursing staff and caring staff. **Maria** said she was on a committee that was trying to put structures in place (at the clinics) whereby each caregiver had a clear job description, especially regarding the hours she had to work and what was expected from her every week. Therefore, in an attempt to achieve legal backing, **Maria** would like to see VCGs inserted as a sub-group (they are not there at present), and that they are given a scope of practice that is made legal. **Maria** said that from a nursing perspective, there was accountability and acts of omission and legislation. So nurses had to follow a scope of practice. She felt that a scope of practice should be written up that could be adhered to and that the caregivers need to agree to it and sign it. In this way, if they are given the title: "Home-Based Carer" then they would have a particular scope of practice and if they go beyond it then obviously there will be consequences because people's lives could otherwise be at risk. **Sarah** said that in her organisation all the volunteers had a scope of practice, or a scope of work, and they all enter into a written contract with the organisation. At the time of the interview, **Sarah** explained that the organisation was developing new contracts for their volunteers.

A related point that emerged was the need to limit the hours that volunteers work caring for clients, especially in cases where CHBC agencies are unable to pay them a stipend. **Sarah** suggested placing a limit on how much work caregivers can do. **Maria** too raised this issue:

> *We agreed on four hours a day and a R1000 a month at the group that I'm with ... the government is giving a R1000 a month, and then it was decided that four hours a day was fair. But that's four hours a day of work, not walking to work. ... so we went really deep into the logistics of, "Ok, so you're the home-based carer. How do you get to these homes?"*

Thus, an important aspect concerning the limiting of hours is that of proximity between caregiver and clients. It is the responsibility of CHBC agencies to ensure that their caregivers are managed correctly with regard to the number of clients in their care and how far these clients are from their homes.

In the context of social capital theory, the concept of scope of practice falls under structural social capital. Structural social capital includes roles, rules, precedents and procedures (Uphoff, 2000) and scope of practice includes all of these elements. Its purpose is to contribute towards mutually beneficial collective action (Uphoff, 2000). If all the stakeholders in the domain of CHBC know what is expected of them, the process of CHBC will be that much more effective. If CHBC is more effective, this will positively impact on the quality of care provided to the clients. Introducing a scope of practice, **Maria** said, *"would improve quality and needs to be something that we would have to put in place."* Essentially, a scope of practice would ensure standardisation in terms of expectations. Furthermore, quality care is also based on the ability of CHBC programmes to "meet contractual obligations [and] maintain compliance with established standards" (Namibia's Ministry of Health and Social Services, 2007, p. 43).

Therefore, a scope of practice, starting at the training stage, would help to regulate the competencies and boundaries of the volunteers and thus help to protect clients and organisations from litigation, reduce work tension, and prevent caregivers from being abused and suffering burnout. Standardising a scope of practice for caregivers across the NMBM would help to protect caregivers and clients from the dangers posed by not having a scope of practice. Limiting hours of caregivers would also be a positive step. An ideal situation would be where volunteering and CHBC become a legislated domain, and therefore a controlled form of care, leading to better protection of all CHBC stakeholders, improved social capital and thus higher quality care.

5.5. Conclusion

In conclusion, this chapter has looked at three overall themes. The first was socio-economic structures and their effects on the quality of CHBC. Under this theme, the effects of poverty and unemployment and compensation were discussed. The second theme was the support received by clients and caregivers within CHBC organisational structures and the influence of this support on quality CHBC. Within this theme, the benefits of CHBC to clients and volunteers were investigated. The third theme was addressed structural challenges to improve the quality of CHBC. In this theme, the training of VCGs, monitoring and evaluation, and scope of practice and the need for parameters and legal boundaries were covered. Throughout each of the three themes, the findings of this research project were related to the concept of social capital. Furthermore, the findings were also analysed in order to determine what constitutes quality care in order to answer the research questions.

CHAPTER 6

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

6.1 Introduction

This chapter provides a summary of the research project in relation to the studies' research questions. Furthermore, conclusions are drawn from the findings and linked to the quality care dimensions of the World Health Organisation (WHO) (2006), the United States Agency for International Development's (USAID's) (n.d.), and Franco et al. (2002). In addition, the limitations of the study are presented followed by recommendations with regard to bringing about quality community home-based care (CHBC) and possible future research.

6.2 Summary and conclusion of the study

The overall aim of this research study was to come to a deeper understanding of what is meant by quality CHBC. The study made use of a literature review of CHBC, presenting the background to CHBC and also literature on quality care. The study made use of a qualitative approach with a phenomenological worldview to investigate the concept of quality CHBC. The study was primarily qualitative but also contained a quantitative element, which was essentially for the purposes of enriching the background data of the participants of the study. The theoretical lens through which the study was conducted was social capital theory, which lends itself to the strong community aspect that constitutes CHBC. The data was collected using a variety of research methods, namely: one-on-one interviews, focus group interviews and self-administered questionnaires.

Regarding the research questions of the study, the overarching research question was: *"What is quality CHBC?"* In addition, the study asked three secondary research questions and underneath each secondary research question were a series of more specific sub-questions. The following section presents each of the secondary research questions followed by a summary of the research findings as they relate to the respective research questions.

6.2.1 **Research question 1:** *“What is the socio-economic context of CHBC and its impact on quality CHBC?”*

It was found that certain socio-economic factors played an important role in affecting the quality of care provided by the volunteer caregivers. These factors are in most cases out of the control of the volunteers as they form part of the social milieu in which both the volunteers and their clients find themselves. The two socio-economic factors that were identified and discussed were poverty and unemployment and the accompanying need for compensation for volunteer caregivers. Related to poverty were the problems of poor living conditions and a lack of food security. Related to unemployment, were the reasons people chose to volunteer, especially in relation to the desire for financial reward which was linked to the issue of stipends.

6.2.1.1 Poor living conditions

Concerning poverty, it was found that poor living conditions were a direct consequence of poverty and were a reality for many of the participants in this study, thus making them vulnerable to opportunistic diseases. In addition, such poor living conditions affect volunteer caregivers’ ability to provide quality care and it also affects the social capital of the communities where such conditions occur, which in turn impacts on the quality of care being provided. Hence, with regard to the dimensions of quality care listed by the WHO (2006) and Franco et al. (2002), the poor living conditions of the clients in this study mean that achieving high levels of quality care is a serious challenge, because of a lack of amenities, both on the part of the clients and the volunteers. Furthermore, poor living conditions may mean that for some clients living in such situations they are receiving care which is neither effective nor equitable. This suggests that the care in this study is not of a high quality.

6.2.1.2 Lack of food security

Another challenge that was raised concerning poverty was the problem of food security, which has the effect of placing pressure and frustration on volunteer caregivers in their work with their clients. Thus, it was argued that poverty and a lack of food impacts negatively on the quality of care that the volunteers are able to provide to their clients. In addition, a lack of food security is closely linked to diminished social capital amongst people who are living in poverty. Regarding the quality dimensions, a lack of access to food leads to ineffective and inefficient care (WHO, 2006; USAID, n.d.; Franco et al., 2002). Providing food security for its citizens is a tremendous challenge for the South African government and is an issue that cannot be oversimplified, especially as access to adequate food and water is a basic human right enshrined in the South African Constitution.

6.2.1.3 Reasons for volunteering

The findings suggest that volunteer caregivers choose to volunteer owing to two main reasons namely a desire to obtain employment, and a desire to gain stipends. However, a third reason was identified in the study, namely a love for caregiving. It is argued that a love for caregiving has the ability to increase quality of care. On the other hand, when financial factors dominate volunteer caregivers' reasons for volunteering, quality CHBC can be negatively affected. However, if financial motivations are combined with a love of caregiving, it may have a positive impact on social capital. If the decision to become a volunteer caregiver is based on financial rewards, care may be less patient-centred and interpersonal relations between the volunteers and their clients may be weakened (WHO, 2006; USAID, n.d.; Franco et al., 2002).

6.2.2 **Research question 2:** *What support do volunteer caregivers and their clients currently receive inside and outside of CHBC organisations, and how does this impact on quality CHBC?"*

The research examined the advantages of CHBC as they relate to clients and caregivers and their contributions to quality care. It looked at how CHBC benefits the clients of volunteer caregivers, especially with its focus on counselling. It also looked at how CHBC benefits the volunteer caregivers, because of the different forms of social support that they are able to access: from peers, supervisors, family and their local communities.

6.2.2.1 Psycho-social and spiritual counselling

The benefits that clients can obtain from CHBC services include psycho-social counselling and spiritual counselling as provided by the volunteer caregivers. Both types of services are an integral part of holistic care. The holistic nature of CHBC means that in addition to physical care there is also a counselling aspect. It was noted how the holistic nature of CHBC contributes to an increase in the quality of CHBC. By providing psycho-social and spiritual counselling to their clients, volunteer caregivers have the potential to instil a sense of hope in their clients, thus adding to the quality of care they receive. In addition, the need for trust and confidentiality in the caregiver-client relationship was highlighted as an important element that contributes to quality CHBC provided that such confidentiality is upheld. Where CHBC organisations provide the holistic care as described, they will tend to be more patient-centred and interpersonal relations between their caregivers and clients will be stronger. Hence, from the perspective of the quality care dimensions of the WHO (2006) and Franco et al. (2002), the quality of care would be enhanced.

6.2.2.2 Support for volunteer caregivers

The findings indicated that the support received from various role players within CHBC structures as well as from outside CHBC structures made an important contribution towards assisting the volunteer caregivers in providing their clients with quality care.

- *Supervisor support*

First, the findings clearly show that the supervisors to these caregivers are a great support to them, as the volunteers in the study felt that they can obtain practical guidance and advice from their supervisors as well as receiving spiritual care and counselling from them. Regular consultation with their supervisors about difficult situations concerning their clients helps the volunteers to better care for their clients.

- *Peer support*

Second, there is a scarcity of literature regarding peer support among volunteer caregivers, but the responses of the caregivers demonstrate that it is an important aspect of CHBC. The support that the volunteer caregivers give one another impacts on the care that they provide to their clients, as it assists them with regard to making referrals to the relevant health care professionals and to making informed decisions regarding the health of their clients.

- *Community support*

Third, community members are able to assist the volunteer caregivers to find clients through referrals and can also play an important part in providing volunteer caregivers with emotional support. While this support can indirectly improve the quality of care, negative community involvement, such as the perpetuation of stigma, can be destructive to the work of volunteer caregivers. Thus it is crucial that communities encourage their caregivers in order that these caregivers may be effective in their work. Furthermore, there are positive effects of this community support on social capital and in turn also on improved quality care. Regarding community support, having the community's support inspires the caregivers to keep going as caregivers,, because it gives them an added sense of meaning to their work. The findings showed that most of the volunteers felt that their communities supported them in their work as volunteer caregivers.

- *Family support*

The degree to which families, notwithstanding inherent drawbacks, can offer practical and psychological support to caregivers impacts on their work. The findings in this regard were very encouraging, because the families were clearly supportive of the CHBC work that the volunteer caregivers undertook to provide. It suggests that it is possible that the majority of caregivers' families in this study did not stigmatise persons living with HIV or AIDS (PLHAs) and they approved of community work and CHBC. This suggestion would however need to be more thoroughly researched.

The support that the caregivers receive from the role players mentioned above has the potential to lead to efficient and effective care. Furthermore, with regard to the supervisor and peer support, their guidance and advice could increase the safety factor for the caregiver and the client, for example, in the area of universal precautions where supervisors can instruct their volunteers during in-service training regarding the universal precautions. Community support could also help to maintain the continuity of care through effective referrals. Hence, where there is a strong support base for a caregiver, the care that he or she provides is more likely to be in accord with the quality care dimensions of the WHO (2006), USAID (n.d.) and Franco et al. (2002).

6.2.3 **Research question 3:** *"What structural challenges need to be overcome to enable volunteer caregivers to provide quality CHBC?"*

The findings indicated that the structural challenges required to improve quality CHBC included the need for quality training of the volunteer caregivers. Aspects that needed to be addressed with regard to training were the implementation of a strict screening or selection process when appointing new volunteers; the need to keep the volunteers' education levels in mind when arranging training for them; the importance of standardizing training programmes and the need to train volunteers to have multiple skills. In addition to training, the findings indicated the need for effective monitoring and evaluation systems to be in place. Three aspects addressed the issue of monitoring and evaluation, namely government's role, the current reliability of monitoring and evaluation and the role of mentoring and supervision. Overall it was clear that monitoring and evaluation are critical for quality CHBC to take place. Finally, the need for a scope of practice was highlighted and that the parameters and legal boundaries of volunteers need to be clearly marked to ensure quality CHBC.

6.2.3.1 Personal attributes of volunteer caregivers

Quality care is closely linked to the abilities and personal attributes of the volunteer caregivers who provide the care to their clients. Participants indicated that compassion and emotional maturity were important personal criteria needed by the volunteers. In addition, the age, size and weight of the volunteers can affect the way they provide physical care work. Furthermore, the respondents emphasised the importance that volunteers be capable of upgrading their CHBC skills, indicating that volunteers require a good education. If the personal attributes of the volunteers meet the criteria mentioned above then this will add to their levels of technical competence. Furthermore, their care has the potential to be more effective, efficient and safe and thus complying with the quality care dimensions of the WHO (2006), USAID (n.d.) and Franco et al. (2002).

6.2.3.2 Training of volunteer caregivers

The quality of training that the volunteer caregivers receive has a direct bearing on the quality of care that the clients receive. Furthermore, if the caregiver is not suitable from an educational perspective, this will also have an impact on the quality of care that he or she is able to provide. Hence, if the volunteers are well trained this will add to their levels of technical competence, and as with personal attributes, their care has the potential to be more effective, efficient and safe and thus be in line with the quality care dimensions of the WHO (2006) and Franco et al. (2002).

6.2.3.3 Standardisation of training programmes

Furthermore, some of the participants raised the issue for the need for standardised training programmes. In order for standardisation of training to occur there needs to be strong support from government. The expense or cost of training is also an issue and this is where the need for government funding is required to improve the standards of training and therefore the standards of CHBC. Of course the role of civil society organisations and their ability to source local, national and international funding for training is also critical. There is a need to standardise training in order to raise the quality of CHBC programmes. It was clear in this study that not all CHBC programmes were of the same standard. Better training should impact directly on the quality of care provided to the caregivers' clients. Indeed, it has the potential to lead to care that is effective and efficient and that maintains the continuum of care and therefore complies with the quality care dimensions of the WHO (2006) and Franco et al. (2002).

6.2.3.4 Multiple skills

In order to provide quality holistic care, the volunteers need to be equipped to have multiple skills. Certain CHBC programme managers spoke about the importance of providing holistic care to their clients. The results showed that more volunteers needed training in First Aid, tuberculosis (TB) and caring for orphans and vulnerable children (OVCs). Hence, the way forward for CHBC would be to equip the caregivers to provide holistic care. One of the benefits of CHBC is that the volunteer caregivers are also able to train the families of their clients how to care for their sick family members. Holistic care is person-centred and relies on interpersonal relations, which lead to more effective care (WHO, 2006; Franco et al., 2002).

6.2.3.5 Monitoring and evaluation

There was a general consensus among the participants that monitoring and evaluation is critical for a successful high-quality CHBC system. Most monitoring and evaluation systems in CHBC are about completing forms for statistical purposes. A weakness of the monitoring process is that it can encourage or open up the possibility for unintentional inaccuracy or dishonesty. In addition, it was noted that CHBC is less suited to numerical indicators, because of the range of variables involved. It was suggested that more emphasis be placed on the relationship of the supervisor with the volunteers and the need for the volunteers to report back on their caregiving experiences. The suggestion of a contract between the caregiver and the client helps to ensure that expectations from both the volunteer and the client's perspective are reasonable. Monitoring and evaluation systems have the potential to encourage CHBC organisations to be effective, efficient and safe as indicated by the WHO (2006) and Franco et al. (2002) for quality care to occur.

6.2.3.6 Mentoring

The findings revealed that caregivers need mentoring in the form of continuous support. A good mentor is one who leads by example, has a strong work ethic, has extensive knowledge and has a nurturing relationship with volunteers. Unfortunately, CHBC organisations face the challenge of a shortage of mentors who can provide effective mentoring and this will have a negative effect on the quality of care. Mentoring, like monitoring and evaluation, has the potential to bring about effective, efficient and safe care (WHO, 2006; Franco et al., 2002). However, a shortage of mentors suggests that achieving effective, efficient and safe care is going to be very difficult.

6.2.3.7 Scope of practice

A scope of practice is very important because it can help to regulate the competencies and boundaries of the volunteers and thus help to protect their clients from being exposed to irregular practices, and therefore add to their quality of care. On the other hand, by protecting the volunteers from crossing the boundary of their competency, they themselves will be protected from any litigation. The implementation of a scope of practice can also help to prevent volunteer burnout and this in turn will benefit their clients as they will be better equipped to provide quality care. An ideal situation would be where volunteering and CHBC become a legislated domain, and therefore a controlled form of care leading to better protection of all CHBC stakeholders and thus higher quality care.

6.3 Limitations

A number of boundaries or limitations of the study were identified. First, the number of participants in the structured interviews with the caregivers and clients was too small to generate useful inferential statistics. Second, the structured interview schedules were very long and this meant that the interview process was very drawn out. Long interviews posed a challenge to both the interviewers and interviewees, which may have had an effect on the quality of the responses. Third, the interviewers who conducted the interviews may have benefitted from more training whereby they were skilled in the use of probing questions in order to draw out more comprehensive responses from the participants.

6.4 Recommendations

- **Poverty**

Overall, one of the most obvious, but most difficult ways to improve the quality of CHBC is the eradication of poverty. However, if the problem of poverty was removed, there would probably be no need for the existence of CHBC. Unfortunately, poverty is unlikely to disappear from South Africa just yet. However, this does not mean that the problem of poverty should not be addressed. In order to make a difference in the fight against poverty some form of government intervention is required. Hence, solving the problem of poor living conditions, food insecurity and unemployment also requires government involvement. Yet, government involvement alone will not solve these problems. Civil society organisations are also important role players in this regard and in fact all the CHBC programmes in this study were run by NPOs. It is crucial that the government works closely with civil societies and at the same time acknowledges its responsibility (in the context of CHBC) towards one of the most vulnerable groups in society, namely poor, unemployed, chronically ill people.

- **Government’s role in CHBC**

In the context of CHBC, government’s role is that of driver, leader and facilitator. It is sometimes expected that civil society organisations drive the CHBC process, but they do not have the same authority as the Department of Health (DoH) and the department of Social Development (DSD). Government has the ability to put in place the necessary structures to enable CHBC and its relevant role players to operate at optimum levels. It also has the authority to make changes and to enforce rules. Furthermore, it has the ability to unite CHBC organisations and can create the necessary conditions that can lead to increased social capital.

Government also needs to consider refining the current DoH (2001) *National Guideline on Home-Based Care / Community-Based Care*. It needs to make very clear the expectations that the various stakeholders should have in relation to their respective roles. The guideline is very comprehensive, but it could be more useful if it were more specific regarding issues around management and the relation between the different stakeholders. It might also be useful to develop a handbook to accompany the guideline that addresses in detail the different aspects of CHBC.

- **Monitoring and evaluation**

The role of government in the monitoring and evaluating of CHBC programmes is also very important. At every level the various role players involved in CHBC need guidance on how to monitor and evaluate their respective organisations. By insisting that government be involved at all levels of monitoring and evaluation does not mean that it has to conduct the monitoring processes or the evaluations itself. Its role would be to co-ordinate civil society organisations to either undertake regular evaluations of CHBC organisations or to appoint such organisations to train CHBC organisations how to monitor their programmes. The knowledge transfer from the civil society organisations to the various role players in CHBC organisations and their programmes is linked to bridging ties. By facilitating such processes government would actually be developing relationships between different organisations, which would lead to a strengthening of social capital within the organisations and the communities in which they are located.

- **Mentoring and supervision**

One of the findings of the study highlighted the importance of the volunteer-supervisor relationship and how the supervisors are able to support and guide their volunteers if they meet regularly to discuss their clients' situations. The support that mentors-supervisors give their volunteers plays an important role in maintaining quality CHBC.

One of the challenges of CHBC organisations is finding suitable mentors and supervisors to assist them with their caregiving work. A database of retired nurses who could be drawn into the mentoring role would prove very useful for CHBC organisations.

- **Scope of practice and training**

There is a great need for volunteer caregivers to have a scope of practice by which they can know their boundaries and competencies. However, ideally the scope of practice should be applied across the country and hence there is a need for standardisation. Standardization can only occur if the South African government intervenes to ensure that a standard scope of practice for volunteer caregivers is developed and implemented. Closely linked to the scope of practice is CHBC training of volunteer caregivers. Ideally, the training of the volunteer caregivers must be governed by a scope of practice to ensure that volunteers are not trained in skills that are beyond their function as caregivers. CHBC organisations could develop their own scope of practice for their volunteers, but this would mean that each CHBC organisation would have a different scope of practice and the boundaries of work would differ from organisation to organisation. It is inevitable that at some stage the government will need to step in to ensure that the CHBC volunteers scope of practice is standardised and that a standard training programme be implemented to ensure that all caregivers receive training of a high standard and that the training given does not extend beyond the volunteers’ scope of practice.

6.5 Additional dimensions of quality care

The research identified two other dimensions of quality care that could be added to the list compiled by the WHO (2006) and Franco et al. (2002), namely holistic care and volunteer support. Volunteer support can be further divided into organisational support and non-organisational support.

First, a dimension that could be linked to the “patient-centred dimension” of quality care of the WHO (2006) document is the need for holistic care. Holistic care also requires that CHBC be patient-centred and that the volunteers approach the client in this manner. However, for a volunteer to provide holistic care they need to be equipped to do so. In other words, they need to undergo quality training in CHBC and related courses. Holistic care requires the volunteer to approach the patient fully aware that the patient has physical, psycho-social and spiritual needs.

Second, another quality care dimension which focuses on the volunteer is the need for support systems. A well organised CHBC programme has organisational support consisting of supervision/mentor support and peer support. Outside the organisation there are two kinds of support namely family support and community support. In both cases, the support from the organisation and outside the organisation can be nurtured to the benefit of the client. Such support, if in place and operating successfully, could make an important contribution to the social capital of the communities where CHBC is taking place. Furthermore, it could add to the quality of care being provided by the volunteers to their clients.

6.6 Recommendations for future areas of research

Thus, a key area of future research would be research into the refinement of the DoH (2001) *National Guideline on Home-Based Care / Community-Based Care*. A second important area of research would be the development of a scope of practice for volunteer caregivers. Third, the government's role in monitoring and evaluation needs to be made explicit and the need for the government to coordinate or facilitate monitoring and evaluation of CHBC organisations in order for it to be standardised are other important areas of research. Fourth, research into the standardisation of training programmes is very important because not all volunteers are provided with the same level of education and skills. Fifth, the relationship between government institutions and civil society organisations and the policies that govern their relationship need to be examined in order for the CHBC system to maintain and sustain the continuum of care. Finally, there is a need for more research looking at the relationship between social capital and quality CHBC.

6.7 Conclusion

To conclude, this chapter presented a summary of the thesis and drew conclusions based on the findings. Furthermore, it also set out the limitations of the study. Thereafter, it provided recommendations for improving quality CHBC and suggestions for future studies in the field of CHBC. A core aspect of all the above recommendations is the central role of government as an overall coordinator of the system of CHBC as there needs to be a link between civil society structures and government, and only government has the authority over both.

The challenge is to help CHBC organisations to assist their volunteers to alleviate the poor living conditions of their clients to the degree that quality care is at least a possibility. As already indicated, there are certain positive aspects of CHBC. There are some aspects that benefit the client directly and some aspects that benefit the volunteer caregiver and these aspects have a positive impact on the client too. The client will also benefit from the holistic nature of CHBC where physical care and counselling are provided.

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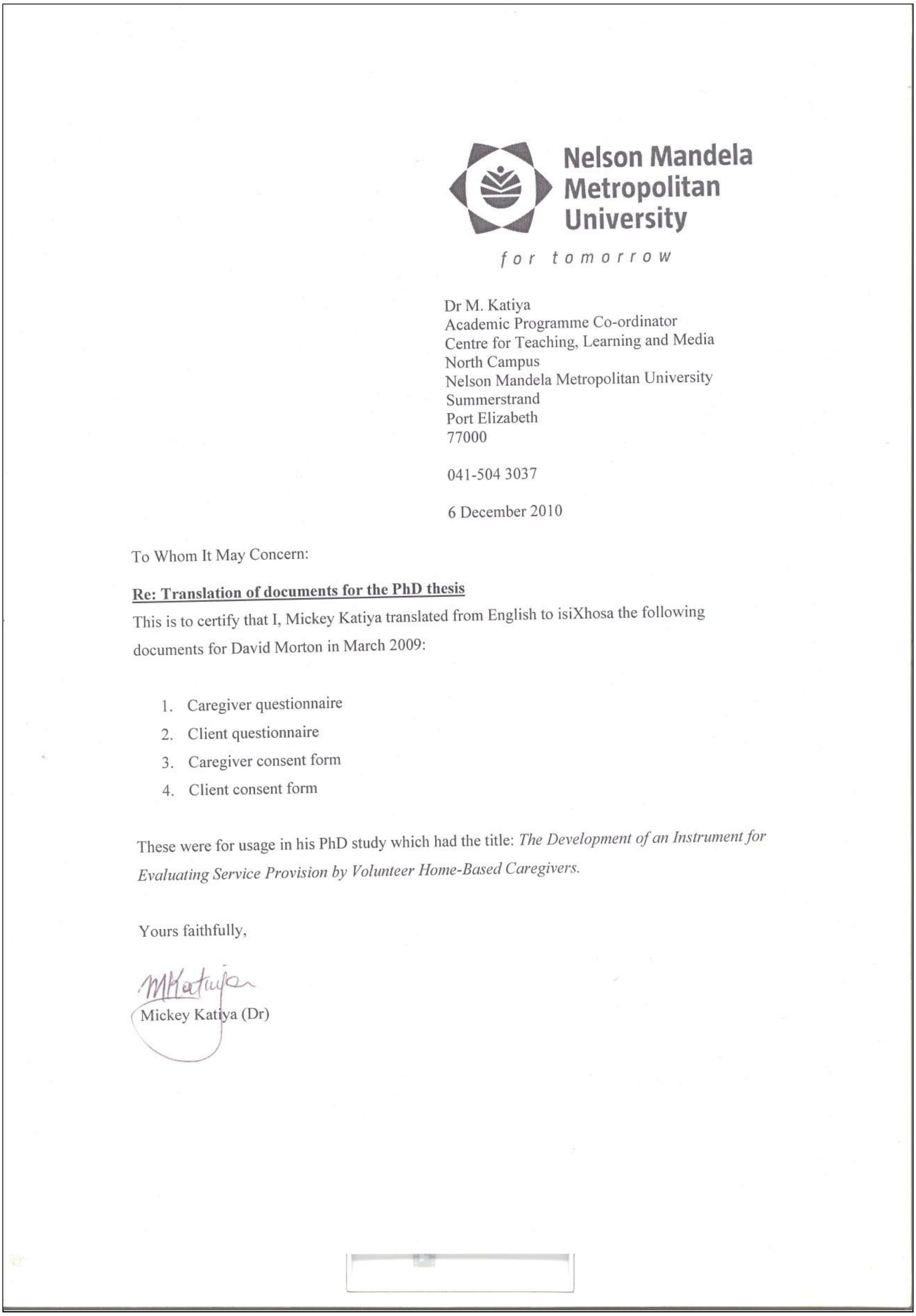
APPENDIX A:

Signed translators’ declarations:

Xhosa and Afrikaans



Nelson Mandela
Metropolitan
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for tomorrow

Dr M. Katiya
Academic Programme Co-ordinator
Centre for Teaching, Learning and Media
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Nelson Mandela Metropolitan University
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Port Elizabeth
77000

041-504 3037

6 December 2010

To Whom It May Concern:

Re: Translation of documents for the PhD thesis

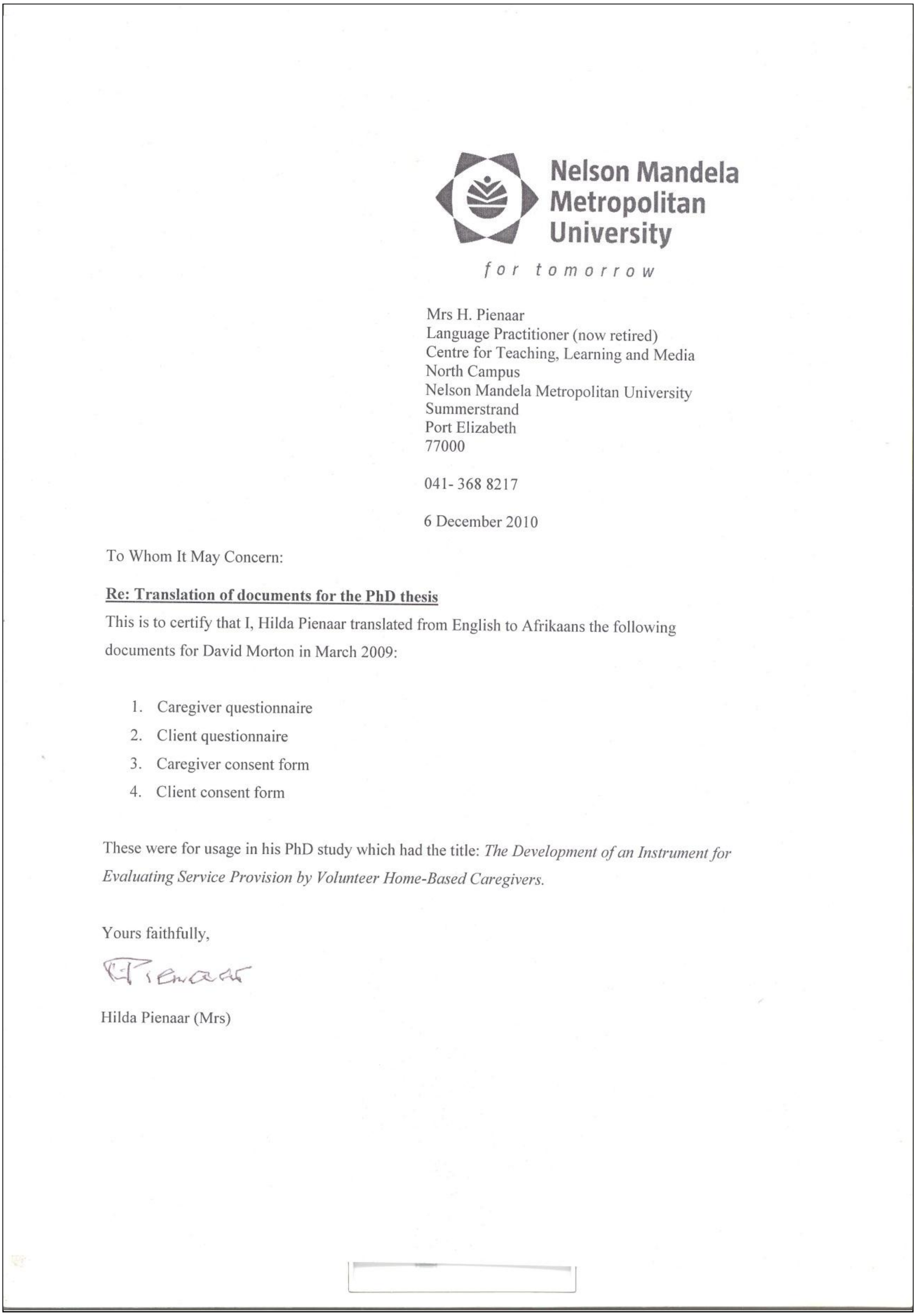
This is to certify that I, Mickey Katiya translated from English to isiXhosa the following documents for David Morton in March 2009:

1. Caregiver questionnaire
2. Client questionnaire
3. Caregiver consent form
4. Client consent form

These were for usage in his PhD study which had the title: *The Development of an Instrument for Evaluating Service Provision by Volunteer Home-Based Caregivers.*

Yours faithfully,

Mickey Katiya (Dr)



Nelson Mandela
Metropolitan
University

for tomorrow

Mrs H. Pienaar
Language Practitioner (now retired)
Centre for Teaching, Learning and Media
North Campus
Nelson Mandela Metropolitan University
Summerstrand
Port Elizabeth
77000

041- 368 8217

6 December 2010

To Whom It May Concern:

Re: Translation of documents for the PhD thesis

This is to certify that I, Hilda Pienaar translated from English to Afrikaans the following documents for David Morton in March 2009:

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4. Client consent form

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Yours faithfully,

Hilda Pienaar (Mrs)

APPENDIX B:

NPO Manager participants:

Subject information sheet, consent form and questionnaire

APPENDIX B

Subject Information Sheet for NPO Manager Participants

Dear prospective participant,

My name is David Morton. I am a doctoral student in sociology at the Nelson Mandela Metropolitan University (NMMU). As part of my degree, I am conducting a research study on volunteer home-based caregivers.

The main aim of this study is to determine the quality of the care that is provided by volunteer home-based caregivers in the Nelson Mandela Metropolitan Municipality.

I wish to invite you to participate in my study. Please note that your participation is voluntary and that non-participation will have no negative consequences. Should you decide to participate in this study, an interview will be conducted.

Please note that you can withdraw from the study at any time, should you feel that you do not want to continue. If you feel that some of the questions are too personal or if you feel uncomfortable answering them, you have the right to refuse to answer, should you wish to do so. Under no circumstances will any of your responses be shown to anyone other than my two research supervisors and myself. No identifying information will be included in the final report.

To make the interview process easier for me, I would like to make use of a tape/voice recorder, with your permission. However, if you are uncomfortable with this arrangement, I will refrain from using one.

Your participation in this study will help with the monitoring and improvement of the quality of care that is provided by the community home-based care programme. This in turn will benefit the clients of the caregivers.

The outcomes of this research will be sent to all the organisations that took part in the study and from which you can access the study results if you so wish.

Yours faithfully,

David Morton

(Researcher)
Tel: 076 461 1868

Professor T.V. Mayekiso

(Research supervisor)
Tel: 041-504-2187

CONSENT

I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study.

Participant name printed *Participant signature* *Date*

Name of Person Conducting Informed Consent Discussion/
Witness
(Printed)

Signature of Person Conducting Informed Consent Discussion/
Witness
Date

Investigator signature (if different from above) Date

1. What is the full name of your organisation?

2. Are you the manager of this organisation?

3. What is your highest qualification?

4. Have you completed any health-related training courses?

5. Who started your organisation?

6. What is his/her highest qualification? (If it isn't the same person)

7. When was it started?

8. Is it a registered non-profit organisation, CBO or NGO?

9. When was it registered?

10. How many volunteer caregivers work in your organisation?

11. How many nurses/supervisors work in your organisation?

12. How many volunteer caregivers does each nurse supervise?

13. How many clients are provided with home care in your organisation?

14. On average how many clients does each volunteer care for?

15. What areas do your caregivers cover?

16. How do you decide who can or who cannot be a volunteer caregiver in your organisation?

17. Do your volunteer caregivers receive an income or stipend or petrol money? Please explain?

18. Do you have to pay rent for your premises?

19. Do have or have you had sponsorship?

20. What services does your organisation offer to its clients?

21. In your opinion, what is quality care? Please describe?

22. Are you willing to let me interview your supervisors/nurses, volunteer caregivers and clients?

23. Have you ever had any form of monitoring or evaluation undertaken at this organisation?

24. If yes, who did it for you?

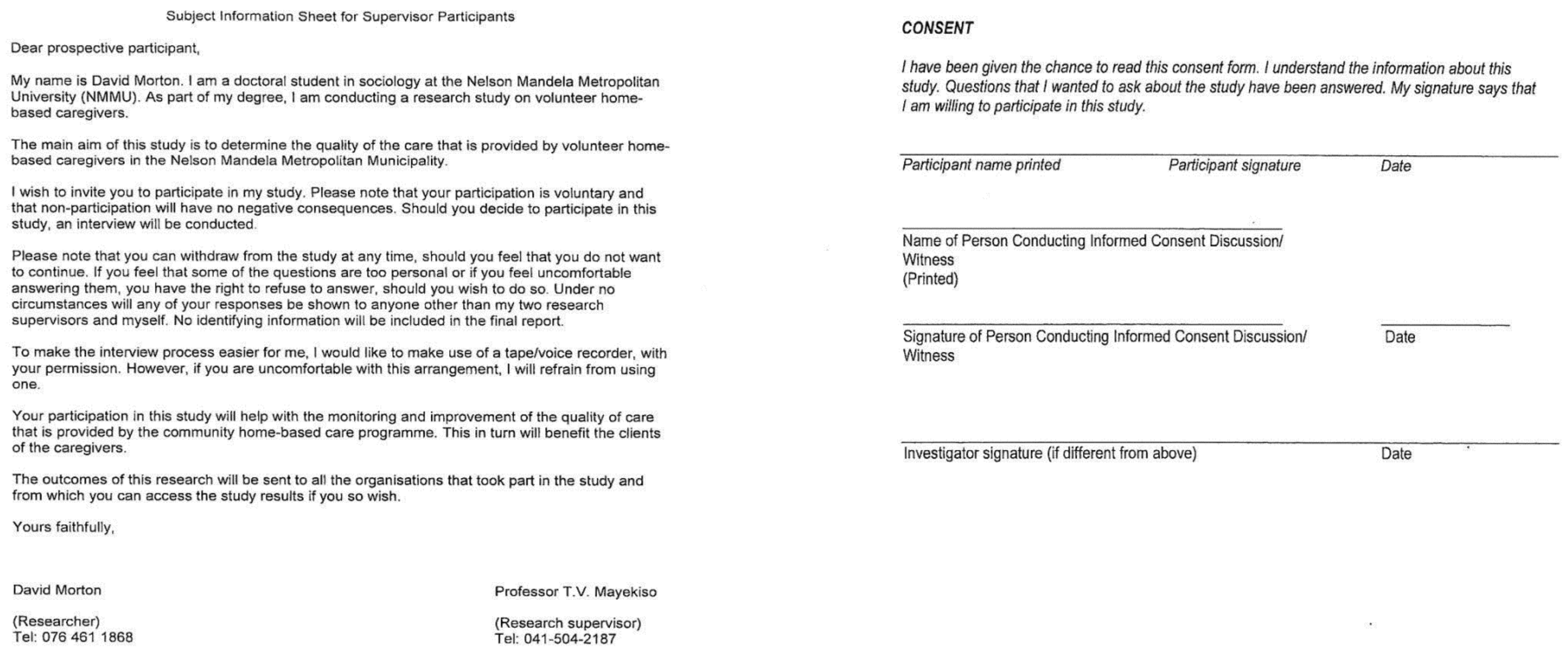
25. If yes, please explain what took place?

APPENDIX C:

Supervisor participants:

Subject information sheets, consent forms and questionnaire

APPENDIX C



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Yours faithfully,

David Morton

(Researcher)
Tel: 076 461 1868

Professor T.V. Mayekiso

(Research supervisor)
Tel: 041-504-2187

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Witness
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Witness

Investigator signature (if different from above) Date

APPENDIX C

Subject Information Sheet for Supervisor Participants

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Yours faithfully,

David Morton	Professor T.V. Mayekiso
(Researcher) Tel: 076 461 1868	(Research supervisor) Tel: 041-504-2187

CONSENT

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Name of Person Conducting Informed Consent Discussion/
Witness
(Printed)

Signature of Person Conducting Informed Consent Discussion/ Date
Witness

Investigator signature (if different from above) Date

Research Project for the Development of a Monitoring / Evaluation Instrument of Volunteer Community Home-based Caregivers

Supervisor Questionnaire:

1.	Today's date: (Day/Month/Year) (e.g. 21/03/2009)	Day	Month	Year
2.	Informed consent obtained? Yes = 1 No = 0			
3.	Which Community Home-Based Care Agency does the supervisor / nurse / team leader work for?			
4.	Location of interview:			
5	Start time:			

Section A – Demographics

1.	How long have you worked at this CHBC agency? (Year(s) and/or Month(s))		
2.	Gender (Male = 1; Female = 0)		
3.	How old were you on your last birthday?		
4.	What is your marital status?	A. Married B. Cohabiting C. Divorced D. Widowed E. Single/Never married	
5.	What is your highest level of education?	A. No formal education B. Grade 0 – 3 C. Grade 4 – 7 D. Grade 8 – 9 E. Grade 10 – 12 F. Tertiary (specify) ____________________	
6.	What is your population group?	A. African B. Coloured C. Indian D. White E. Don't know F. Other (specify) ____________________	
7.	What is the main language that you speak at home?	A. English B. IsiXhosa C. Afrikaans D. Other (specify) ____________________	
8.	To what faith do you belong?	A. None B. Christian C. Muslim D. Hindu E. Jewish F. Other (specify) ____________________	
9.	How important is your faith or religion to you?	A. Not important at all B. Unimportant C. Important D. Very important	
10.	In what neighbourhood do you live?		
11	Are you employed outside the agency? Yes = 1 No = 0		
12.	If yes, what are you employed as?		
13.	Would you describe your work status as:	A. formally employed B. casually employed C. self-employed D. pensioner E. unemployed F. Other (specify) ____________________	
14.	What is your household monthly income? (in rands)	A. 1 – 500 B. 501 – 1000 C. 1001 – 2000 D. 2001 – 3000 E. Above 3000	

Section B – Supervisor

1.	How did you find out about this CHBC agency?	A. Church B. Friend C. Family D. Clinic E. Other (specify) ___________________________	
2.	How long have you been a supervisor? Year(s) and/or Month(s)		
3.	What does your role as a supervisor entail?		
4.	How many VCGs do you have under your supervision?		
5.	How many hours do you work per day as a supervisor at the CHBC agency?		
6.	How many days a week do you work as a supervisor at the CHBC agency?		
7.	How many leave days are you able to take off per year?		
8.	How many days leave did you take off in 2007?		
9.	Do you work on weekends? / Yes = 1 No = 0		
10.	Does your CHBC agency pay you a salary? / Yes = 1 No = 0		
11.	If yes, how much does this CHBC agency pay you per month (in rands)?		R
12.	If no, do you receive a stipend? Yes = 1 No = 0		
13.	Have you worked for any other CHBC agencies before you worked for this one? Yes = 1 No = 0		
14.	If yes, how many other CHBC agencies did you work for before this one? CHBC Agency(ies)		
15.	If you previously worked for a CHBC agency, why did you leave the last one? [You may indicate more than one reason.]	A. I needed more money B. I had a disagreement with management C. It was too much travelling D. I don't have my own transport E. Family reasons F. I had a disagreement with a colleague (s) G. Other (specify) ___________________________	
16	If you previously worked for a CHBC agency, how long did you work for the last one? Year(s) and/or Month(s)		
17.	Do you work for more than one CHBC agency? Yes = 1 No = 0		
18	Can you speak the language of your VCGs? Yes = 1 No = 0		
19.	What do you think are the strengths of your CHBC programme?		
20.	What do you think are the weaknesses of your CHBC programme?		
21.	What areas do you think could be improved? How?		

Section C – Volunteer Caregiver (VCG)

1.	What are the selection criteria used for choosing a suitable candidate for the role of VCG?	
2.	How are clients allocated to a VCG, i.e. what factors determine the allocation of a particular patient to a particular VCG?	
3	Do your VCGs receive on-going training? Yes = 1 No = 0	

4.	Have your VCGs completed the following courses? Could you please indicate if the certificate that was received on completion of the course was a certificate of **competence**, or a certificate of **attendance**? Could you also please state which organisation presented the training course? Space is provided for you to write down any additional courses that were attended by your VCGs.				
	Description of course	**Yes = 1 No = 0**	**Certificate of Competence**	**Certificate of Attendance**	**Which organisation presented the course?**
A.	Home-based care (HBC)				
B.	First Aid				
C.	HIV and AIDS education				
D.	Orphan & Vulnerable Children care				
E.	TB education				
F.	Basic nursing practice				
G.	AIDS counselling				
H.	Bereavement counselling				
I.	Family counselling				
J.	Marriage counselling				
K.	Child counselling				
L.	Volunteer Counselling & Testing (VCT)				
M.	Youth-related				
N.	Nutrition				
O.	Stress management				
P.	Capacitar				
Q.	Retreats				
R.	Physical exercise techniques				
S.	Relaxation techniques				

5.	Please write down any additional comments that you would like to make concerning the training received by your VCGs.	
6	Have your VCGs requested to attend certain courses, or that they be allowed to re-attend them? Yes = 1 No = 0	
7.	If yes, please state which ones.	
8.	What factors do you think prevent or hinder your VCGs taking part in training?	
9.	How confident do you think your VCGs are regarding their level of knowledge of HIV and AIDS?	A. Very unconfident B. Unconfident C. Confident D. Very confident
10.	Please explain the reason for your choice.	

11.	Do you think that they need additional education in HIV and AIDS knowledge? Yes = 1 No = 0	
12.	Please explain.	
13.	Do you think that they need additional training in HBC skills? Yes = 1 No = 0	
14.	Please explain.	
15.	On average, how many clients do each of your VCGs have?	
16.	Is there a maximum number of clients that a VCG is allowed to have? Yes = 1 No = 0	
17.	If yes, what is the maximum number of clients?	
18.	What basic supplies do your VCGs provide for their clients?	A. Food B. Blankets C. Clothes D. Baby milk/formula E. Equipment at home (e.g. mattress; catheter) F. Gauze G. Bandages H. Gloves I. Tea Tree Oil J. Aqueous Cream K. Other (specify) ______
19.	Do your VCGs give their clients medicine to help remove their pain? Yes = 1 No = 0	
20.	If yes, what medicines do they give their clients to help remove their pain?	
21.	Do your VCGs know about Universal Precautions? Yes = 1 No = 0	
22.	Have they been trained to do the following? **Have they been trained to:**	*Yes = 1 No = 0*
A.	Lift a client	
B.	Help a client out of bed	
C.	Teach motion exercises	
D.	Shave a male client	
E.	Feed a client	
F.	Give advice about mouth care	
G.	Measure intake/output	
H.	Teach breathing exercises	
I.	Assist a client who is having oxygen therapy	
J.	Assist a client who is coughing	
K.	Assist a client who is vomiting	
L.	Collect sputum	
M.	Take temperature	
N.	Take pulse	
O.	Put a client in the recovery position	
P.	Put on and take off gloves	
Q.	Make beds	
R.	Position your client on the bed	
S.	Use a wheelchair	
T.	Give pressure care	
U.	Wash hair in bed	
V.	Give hand and foot care	

W.	Give a bedpan	
X.	Give catheter care	
Y.	Test urine	
Z.	Give medicines	
AA.	Help a client who is choking	
AB.	Dispose of sputum	
AC.	Give tepid sponging	
AD.	Stop bleeding	
AE.	Other (specify) ____	
23.	Are there factors preventing your VCGs from providing quality care and support to their clients and their families? Yes = 1 No = 0	
24.	If yes, please explain.	
25.	Have your VCGs ever been asked by a client to disclose his/her HIV status to his/her family? Yes = 1 No = 0	
26.	How many of your VCGs have their own car?	
27.	Do transport problems affect the care work of your VCGs in any way? Yes = 1 No = 0	
28.	If yes, please explain.	
29.	Have your VCGs ever complained of any conflict with their clients in their work as VCGs? Yes = 1 No = 0	
30.	If yes, please explain.	
31.	Would you say that your VCGs are confident in their work as VCGs? Yes = 1 No = 0	
32.	Please explain.	
33.	Are your VCGs part of a care team? Yes = 1 No = 0	
34.	Would you say that your VCGs are confident in their work as VCGs? Yes = 1 No = 0	
35.	If yes, please explain who is in the team.	
36.	How do you rate the clinic / hospital nurses respect for your VCGs?	A. Very disrespectful B. Disrespectful C. Respectful D. Very respectful
37.	Please explain.	
38.	How approachable are the nurses at the clinic and hospital with regard to your VCGs asking for advice?	A. Very unapproachable B. Unapproachable C. Approachable D. Very approachable

39.	Please give an example to explain your answer.	
40.	Have your VCGs ever been evaluated? Yes = 1 No = 0	
41.	If yes, when last were they evaluated? Year(s) and/or Month(s) ago	
42.	Who did the evaluation?	
43.	Did you receive feedback?	
44.	Please explain what took place during the evaluation.	
45.	Who provides your VCGs with psychological support?	
46.	Who provides your VCGs with spiritual support?	
47.	Do the VCGs receive any debriefing? Yes = 1 No = 0	
48.	If yes, please describe.?	
49.	Have you had training in counselling? Yes = 1 No = 0	
50.	If yes, what counselling qualification do you have?	
51.	How many days per month do you have formal meetings with your VCGs?	
52.	How many months per year do you visit the clients of your VCGs?	
53.	What keeps your VCGs motivated?	
54.	What discourages your VCGs in their work?	
55.	What are some of the issues that they discuss with you?	

APPENDIX D:
Volunteer caregiver participants:
Subject information sheets, consent forms and questionnaire

APPENDIX D

Subject Information Sheet for Volunteer Caregiver Participants

Dear prospective participant,

My name is David Morton. I am a doctoral student in sociology at the Nelson Mandela Metropolitan University (NMMU). As part of my degree, I am conducting a research study on volunteer home-based caregivers.

The main aim of this study is to determine the quality of the care that is provided by volunteer home-based caregivers in the Nelson Mandela Metropolitan Municipality.

I wish to invite you to participate in my study. Please note that your participation is voluntary and that non-participation will have no negative consequences. Should you decide to participate in this study, an interview will be conducted.

Please note that you can withdraw from the study at any time, should you feel that you do not want to continue. If you feel that some of the questions are too personal or if you feel uncomfortable answering them, you have the right to refuse to answer, should you wish to do so. Under no circumstances will any of your responses be shown to anyone other than my two research supervisors and myself. No identifying information will be included in the final report.

To make the interview process easier for me, I would like to make use of a tape/voice recorder, with your permission. However, if you are uncomfortable with this arrangement, I will refrain from using one.

Your participation in this study will help with the monitoring and improvement of the quality of care that is provided by the community home-based care programme. This in turn will benefit the clients of the caregivers.

The outcomes of this research will be sent to all the organisations that took part in the study and from which you can access the study results if you so wish.

Yours faithfully,

David Morton

(Researcher)
Tel: 076 461 1868

Professor T.V. Mayekiso

(Research supervisor)
Tel: 041-504-2187

CONSENT

I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study.

Participant name printed *Participant signature* *Date*

Name of Person Conducting Informed Consent Discussion/
Witness
(Printed)

Signature of Person Conducting Informed Consent Discussion/
Witness Date

Investigator signature (if different from above) Date

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Name of Person Conducting Informed Consent Discussion/
Witness
(Printed)

Signature of Person Conducting Informed Consent Discussion/
Witness
Date

Investigator signature (if different from above) Date

Research Project for the Development of a Monitoring / Evaluation Instrument of Volunteer Community Home-based Caregivers

Caregiver Questionnaire
Iphepha lemiBuzo labongi
Versorgersvraelys

1.	Today's date: (Day/Month/Year) (e.g. 21/03/2009) Umhla: (Umhla/Inyanga/Unyaka) Vandag se datum: (Dag/Maand/Jaar)	Day	Month	Year
2.	Initials of interviewer: Oonobumba begama lowenza udliwano ndlebe Voorletters van onderhoudvoerder			
3.	Informed consent obtained? Yes = 1 No = 0 Imvume ifumanekile? Ewe = 1 Hayi = 0 Ingeligte besluit verkry? Ja = 1 Nee = 0			
4.	Record time of interview start: Hour / Minute (e.g. 9.30, or 14.25) Ixesha lodliwano ndlebe: Iyure / Imizuzu Teken die begintyd van die onderhoud aan: Uur / Minute		Hour	Minute
5.	Which Community Home-Based Care Agency does the VCG work for? IVCG isuka kweyiphi i-Arhente yoKongela eMakhaya? Vir watter Gemeenskap Tuisgebaseerde Versorgingsagentskap (GTVA) werk die Vrywillige Tuisversorger (VT)?			
6.	Location of interview: Indawo yodliwano-ndlebe: Plek waar onderhoud plaasvind:			

Section A – Demographics
Icandelo A – Amanani abantu
Afdeling A – Demografie

1.	How long have you worked at this CHBC agency? (Year(s) and/or Month(s)) Usebenze ixesha elingakanani kule arhente yeNNK? (Unyaka/iminyaka okanye liyanga) Vir hoe lank werk u al by hierdie GTVA? (Jaar/Jare en/of Maand(e))	Years	Months
2.	Gender (Male = 1; Female = 0) Isini (Indoda = 1; Ibhinqa = 0) Geslag (Manlik = 1; Vroulik = 0)		
3.	How old were you on your last birthday? Wawumdala kangakanani kumhla wakho wokuzalwa wokugqibela? Hoe oud het u geword op u laaste verjaarsdag?		
4.	What is your marital status? (Circle relevant letter) Lithini inqanaba ngokwemo yomtshato? Wat is u huwelikstatus?	A. Married / Ushatile / Getroud B. Cohabiting / Uyahlalisana / Bly saam C. Divorced / Udivosile / Geskei D. Widowed / Ubhujelwe / Wewenaar/Weduwee E. Single/Never married / Akhuzange utshate / Enkellopend/Nooit getroud nie	
5.	Do you have children? Yes = 1 No = 0 Unabo abantwana? Ewe = 1 Hayi = 0 Het u enige kinders? Ja = 1 Nee = 0		
6.	If yes, how many? Ukuba kunjalo, bangaphi? Indien ja, hoeveel?		
7.	What is your highest level of education? (Circle relevant letter) Lithini inqanaba lakho lemfundo ephakamileyo? Wat is u hoogste opvoedingsvlak?	A. No formal education / Akukho mfundo ilungiselweleyo / Geen formele opvoeding B. Grade 0 – 3 / iBanga 0 – 3 / Graad 0 – 3 C. Grade 4 – 7 / iBanga 4 – 7 / Graad 4 – 7 D. Grade 8 – 9 / iBanga 8 – 9 / Graad 8 – 9 E. Grade 10 – 12 / iBanga 10 – 12 / Graad 10 – 12 F. Tertiary (specify) / Imfundo engasentla kwematriki (chaza) / Tersiêr (spesifiseer) ______________________	
8.	What is your population group? (Circle relevant letter) Loluphi uhlanga lwakho? Aan watter bevolkingsgroup behoort u?	A. African / UmAfrika / Swart B. Coloured / Ilawu / Kleurling C. Indian / Ikula / Indier D. White / Omhlophe / Wit E. Don't know / Andazi / Weet nie F. Other (specify) / Ezinye (chaza) / Ander (spesifiseer) ______________________	
9.	What is the main language that you speak at home? (Circle relevant letter) Luthini olona lwimi uluthetha ekhaya? Wat is die hooftaal wat u by die huis praat?	A. English / isiNgesi / Engels B. IsiXhosa / isiXhosa / isiXhosa C. Afrikaans / iAfrikans / Afrikaans D. Other (specify) / Ezinye (chaza) / Ander (spesifiseer) ____________________	
10.	To what faith do you belong? (Circle relevant letter) Yeyiphi inkolo yakho? Aan watter geloof behoort u?	A. None / Alikho / Geen B. Christian / AmaKrestu / Christen C. Muslim / AmaMaslim / Muslem D. Hindu / AmaHindu / Hindu E. Jewish / AmaJuda / Joods F. Other (specify) / Ezinye (chaza) / Ander (spesifiseer) ______________________	
11.	How important is your faith or religion to you? (Circle relevant letter) Lubaluleke kanjani ukholo okanye inkolo kuwe? Hoe belangrik is geloof of godsdiens vir u?	A. Not important at all / Alubalulekanga kwaphela / Glad nie belangrik nie B. Unimportant / Alubalulekanga / Onbelangrik C. Important / Lubalulekile / Belangrik D. Very important / Lubaluleke kakhulu / Baie belangrik	
12.	In what neighbourhood do you live? Uhlala kobuphi ubumelwane? In watter woonbuurt woon u?		
13	Are you employed outside the agency? Yes = 1 No = 0 Uqeshwe ngaphandle kwe-agente? Ewe = 1 Hayi = 0 Is u buite die agentskap indiens? Ja = 1 Nee = 0		

14.	If yes, what are you employed as? Ukuba kunjalo uqeshelwe ntoni? Indien ja, wat doen u?	
15.	Would you describe your work status as (Circle relevant letter): Ungalichaza inqanaba lomsebenzi wakho njenge: Sal u werkstatus beskryf as:	A. formally employed / ingqesho eyamkelekileyo / formeel indiens B. casually employed / ingqesho yexeshana / informele sektor C. self-employed / ukuziqesha / eie besigheid D. pensioner / odiumhlala-phantsi / pensionaris E. unemployed / ongaqeshwanga / werkloos F. Other (specify) / Ezinye (chaza) / Ander (spesifiseer) ____________________
16.	What is your household monthly income? (in rands) (Circle relevant letter) Wamkela malini ngenyanya? (ngerandi) Wat is u maandelikse huishoudelike inkomste?	A. 1 – 500 B. 501 – 1000 C. 1001 – 2000 D. 2001 – 3000 E. Above / ngaphezu kwama / bo 3000 F. Other (specify) / Ezinye (chaza) / Ander (spesifiseer) ____________________

Section B – Community Home-based Care (CHBC) Agency
Icandela B – I-Arhente yokongiwa koluNtu eKhaya (CHBC)
Afdeling B – Gemeenskap Tuisgebaseerde Versorgingsagentskap

1.	How did you find out about this CHBC agency? (Circle relevant letter) Wayifumana njani le- arhente ye-CHBC? Hoe het u uitgevind van die GTV agentskap?	A. Church / Icawei / Kerk B. Friend / Umhlobo / Vriend C. Family / Usapho / Familie D. Clinic / Iklinikhi / Kliniek E. Other (specify) / Ezinye (chaza) / Ander (specifiseer) ______________________	
2.	How long have you worked at this CHBC agency? Year (s) and/or Month (s) Usebenze ixesha elingakanani kule arhente yeCHBC? Hoe lank werk u al by die GTV agentskap?		
3.	How many hours do you work per day (on average)? / Hour(s) Usebenza iiyure ezingaphi ngosuku? / Iiyure Hoeveel uur werk u per dag? Uur/ure		
4.	How many days a week do you work? / Day(s) Usebenza iintsuku ezingaphi ngeveki? / U/Iintsuku Hoeveel dae per week werk u? Dag/dae		
5.	How many leave days are you able to take off per year? / Day(s) Zingaphi iintsuku onokuzihlala ungaphangeli ngonyaka? / U/Iintsuku Hoeveel dae verlof kan u per jaar neem? Dag/dae		
6.	How many days leave did you take off in 2008? / Day(s) Zingaphi iintsuku ongaziphangelanga ngowama-2008? U/Iintsuku Hoeveel dae verlof het u in 2008 geneem? Dag/dae		
7.	Do you work on weekends? / Yes = 1 No = 0 Uyaphangela ngeempela-veki? Ewe = 1 Hayi = 0 Werk u naweke? Ja = 1 Nee = 0		
8.	Does your CHBC agency pay you a salary? / Yes = 1 No = 0 Ingaba i-arhente yeCHBC ikuhlawula umvuzo? Ewe = 1 Hayi = 0 Betaal die GTV agentskap aan u ‘n salaris? Ja = 1 Nee = 0		
9.	If yes, how much does this CHBC agency pay you per month (in rands)? Ukuba kunjalo, ikuhlawula malini le arhente yeCHBC ngenyanga (ngeerandi)? Indien ja, hoeveel betaal die GTV agentskap aan u per maand (in rande)?	R	
10.	If no, do you receive a stipend? Yes = 1 No = 0 Ukuba akunjalo, uyasifumana isixhaso sentlawulo? Ewe = 1 Hayi = 0 Indien nee, ontvang u ‘n stipendium? Ja = 1 Nee = 0		
11.	If yes, please explain what this stipend consists of and how often you receive it. Ukuba kunjalo, nceda ucacise ukuba esi sixhaso sentlawulo siqulethe ntoni usifumana njani? Indien ja, verduidelik asseblief waaruit die stipendium bestaan en hoe dikwels u dit ontvang:		
12.	How many other CHBC agencies did you work for before this one? Zingaphi ezinye ii-arhente zeCHBC okhe wazisebenzela ngaphambili? By hoeveel ander GTV agentskappe het u voorheen gewerk?		
13.	If you previously worked for a CHBC agency, why did you leave the last one? (Circle relevant letter (**s**)) Ukuba wawukhe wasebenzela i-arhente yeCHBC, wayishiyela ntoni le yokugqibela? [Unokubonisa ngesizathu esingaphezu kwesinye.] Indien u voorheen vir ‘n GTV agentskap gewerk het, waarom het u die vorige een verlaat? (U mag meer as een rede gee)	A. I needed more money / Ndandifumana imali engaphezulu / Ek het meer geld nodig gehad B. I had a disagreement with management / Ndandinesivumelwano nabasemagunyeni / Ek het ‘n meningsverskil met die bestuur gehad C. It was too much travelling / Yayihambisa kakhulu / Daar was te veel ryery D. I don’t have my own transport / Andinaso esam isithuthi / Ek het nie my eie vervoer nie E. Family reasons / Izizathu zosapho / Gesinsredes F. I had a disagreement with a colleague (s) / Ndandingavumelani nogxa wam/ noogxa bam basemsebenzini G. Other (specify) / Ezinye (chaza) / Ander (specifiseer) ____________________	
14.	If you previously worked for a CHBC agency, how long did you work for the last one? / Year(s) and/or Month(s) Ukuba wawukhe wasebenzela i-arhente yeNNK, wasebenza ixesha elingakanani kweyokugqibela? / U/ Iminyaka ne/okanye I/Iinyanga		

	Indien u voorheen vir 'n GTV agentskap gewerk het hoe lank het u by die vorige een gewerk? Jaar/jare en / of maand (e)		

15.	What motivated you to become a caregiver? Wakhuthazwa yintoni ukuze ube ngumnoneleli weembedienge? Wat het u gemotiveer om 'n versorger te word?	
16.	What motivated you to join a CHBC agency? Wakhuthazwa yintoni ukuze ujoyine i- arhente yeCHBC? Wat het u gemotiveer om by 'n GTV agentskap aan te sluit?	
17.	Do you do other volunteer work? e.g. at a clinic, school, church. / Yes = 1 No = 0 Unawo omnye umsebenzi wokuvolontiya? Umz. eklinikhi, esikolweni, ecaweni./ Ewe = 1 Hayi = 0 Doen u ook ander vrywillige werk? Bv. by 'n kliniek, skool, kerk. / Ja = 1 Nee = 0	
18.	If yes, indicate where you volunteer. (Circle relevant letter**(s)** – may circle more than one) Ukuba kunjalo, bonisa ukuba ungavolontiya phi. [Nceda tikisha ibhokisi engqameneyo] Indien ja, dui aan waar u die vrywillige werk doen. (Omkring al die relevante opsies)	A. Clinic / iklinikhi / Kliniek B. Church / Icawe / Kerk C. Soup kitchen / Ikhitshi lesuphu / Sopkombuis D. School / Isikolo / Skool E. Creche / Ikhritshi / Créche F. Orphanage / Indwo yokugcina iinkedama / Weeshuis G. Other (specify) / Ezinye (chaza)/ Ander (spesifiseer) ______________________
19.	What kind of work do you do there? (Circle relevant letter**(s)** – may circle more than one) Msebenzi mni owenzayo phaya? [Nceda tikisha ibhokisi engqameneyo] Watter tipe werk doen u daar? (Omkring al die relevante opsies)	A. I cook food / Ndipheka ukutya / Ek kook kos B. I do nursing work / Ndenza umsebenzi wokonga / Ek doen verpleegwerk C. I do care work / Ndenza umsebenzi wokunonelela / Ek doen versorging D. I teach / Ndiyafundisa / Ek gee onderwys / Ek onderrig E. I supervise / Ndikhangela indlela ekusetyenzwa ngayo / Ek hou toesig F. I do training / Ndenza uqeqesho / Ek doen opleiding G. Other (specify) / Ezinye (chaza)/ Ander (spesifiseer) ______________________
20.	How are your clients referred to you? Bathunyelwa njani abantu kuwe? Hoe word u kliënte na u verwys?	
21.	Can the referral system be improved? Yes = 1 No = 0 Inakho ukuphuculwa indlela yokuthunyelwa kwabantu? / Ewe = 1 Hayi = 0 Kan die verwysingstelsel verbeter word? Ja = 1 Nee = 0	
22.	If yes, can you suggest ways that the referral system could be improved? Ukuba kunjalo, ungayixela inkqubo yokuthunyelwa kwabantu? Indien ja, kan u voorstelle maak van hoe die stelsel verbeter kan word?	

Section C – Training

1.	In the following section please indicate what courses that you have completed (Yes = 1 and No = 0). Please indicate if you received a certificate of competence or attendance. Finally, please state which organisation presented the course. Kweli candela lilandelayo nceda uxele ukuba zeziphi na izifundo / iikhosi ozifunde wazigqiba (Ewe = 1 kunye Hayi = 0). Nceda ubonise Ukuba ufumene isatifiketi senkqubo okanye sokuya. Ekugqibeleni, nceda xela iqumrhu ebeliqhuba isifundo / ikhosi Dui asseblief, in die volgende afdeling aan, watter kursusse wat u voltooi het (Ja = 1 en Nee = 0). Dui ook aan of u 'n sertifikaat van bevoegdheid of bywoning ontvang het. Laastens noem asseblief watter organisasie die kursus aangebied het.				
	Description of course	**Yes = 1 No = 0 Ewe = 1 Hayi = 0 Ja = 1 Nee = 0**	**Certificate of Competence Isatifiketi se inkqubo Sertifikaat van Bevoegdheid**	**Certificate of Attendance Ukuya isatifiketi se Sertifikaat van bywoning**	**Which organisation presented it? Liliphi iqumrhu eliqhube oku? Watter organisasie het dit aangebied?**
A.	Home-based care (HBC) Ukongelwa ekhaya / ukongiwa ekhaya (NK / KK) Tuisgebaseerde Versorging (TV)				
B.	First Aid Uncedo lokuqala Eerstehulp				
C.	HIV and AIDS education Imfundo yeNtsholongwane kaGawulayo noGawulayo HIV en VIGS opvoeding				
D.	Orphan & Vulnerable Children care (OVC) Inkathalelo yabaNtwana abaziiNkedama nabaphatheke kakubi Wees- en Kwesbare Kidnersorg (WKK)				
E.	TB education Imfundo ngeSifo sePhepha / ngeTB TB Opvoeding				
F.	Basic nursing practice Ukonga kokuqala Basiese Verpleegpraktyk				
G.	AIDS counselling Ingcebiso ngoGawulayo VIGS Berading				
H.	Bereavement counselling Ingcebiso ngomphanga Traumaberading				
I.	Family counselling Ingcebiso yosapho Gesinsberading				
J.	Marriage counselling Ingcebiso yomtshato Huweliksberading				
K.	Child counselling Ingcebiso yomntwana Kinderberading				
L.	Volunteer Counselling & Testing (VCT) Ingcebiso loVavanyo nohlolo lwasimahla (CVV) Vrywillige Berading en Toetsing (VBT)				

M.	Youth-related Olungqamene nolutsha Jeugverwant				
N.	Nutrition Isondo Voeding				
O.	Stress management Ulawulo lwesitresi Stresbestuur				
P.	Capacitar Capacitar Capacitar				
Q.	Retreats Uhlaziyo lomphefumlo Stil verblyf				
R.	Physical exercise techniques Iindlela zomthambo Fisiese Oefentegnieke				
S.	Relaxation techniques Iindlela zokuziphumza Ontspanningstegnieke				
T.					
U.					
2.	If you completed any courses not indicated above, please list them in the space provided. Ukuba ufunde wagqiba nokuba zeziphi naizifundo/ iikhosi ezingachatshazelwanga ngasentla, Nceda uzidwelise kwisithuba esishiyiweyo. Indien u enige kursusse wat nie hierbo aangedui is nie, voltooi het, lys hulle in die spasie toegelaat.				
3.	List those courses (both self-care & non-self-care) that helped you the most with your work as a VCG. Dwelisa ezo zifundo/ khosi (zombini zokuzikhathalela nokungazinoneleli/ ukungazikhathaleli) okukuncedileyo nomsebenzi njenge VCG. Lys die kursusse (beide selfsorg en nie-selfsorg) wat u die meeste gehelp het met u werk as TV				
4.	Do you feel better prepared for your care work having received this training? Yes = 1 No = 0 Uziva uzilungiselele ngcono kumsebenzi wakho wokunonelela wakuba ufumene uqeqesho? Ewe = 1 Hayi = 0 Voel u beter voorbereid vir u sorgwerk nadat u hierdie opleiding ontvang het?				
5.	Please explain your answer to Question 6: Nceda chaza impendulo yakho kumbuzo 6: Verduidelik asseblief u antwoord op Vraag 6:				
6.	Are there other courses that you would like to attend or re-attend? Yes = 1 No = 0 Zikhona ezinye izifundo / khosi ongathanda ukuya kuzo okanye ukungayi? Ewe = 1 Hayi = 0 Is daar ander kursusse wat u graag wil bywoon of herbywoon? Ja = 1 Nee = 0				
7.	If yes, please list these. Ukuba kunjalo, nceda dwelisa ezi. Indien ja, lys asseblief.				
8.	How long has it been since you last did training? Year(s) and/or Month(s) ago Lixesha elingakanani ulenzile uqeqesho lokugqibela? Hoe lank was dit sedert u laaste opleiding?			Years	Months
9.	Would you go for training if you had to pay for it? Yes = 1 No = 0 Ungaya kuqeqesho ukuba kungafuneka uluhlawulele? Ewe = 1 Hayi = 0 Sou u die opleiding wou doen as u self daarvoor moet betaal? Ja = 1 Nee = 0				
10.	Have you ever missed a training opportunity? Yes = 1 No = 0 Wakhe waliphosa ithuba loqeqesho? Ewe = 1 Hayi = 0 Het u al ooit 'n opleidingsgeleentheid misgeloop? Ja = 1 Nee = 0				

11.	If yes, what prevented you from taking part? Ukuba kunjalo, wanqandwa yintoni ukungathathi nxaxheba? Indien ja, wat het u verhoed om deel te neem?	
12.	Are you confident in your level of knowledge of HIV and AIDS? (Circle relevant letter) Uqinisekile ngomgangatho wolwazi lwakho lweHIV ne AIDS/ UGawulayo? Is u selfversekerd oor u kennis van HIV en VIGS?	A. Very unconfident / Ukungaqiniseki okukhulu / Baie onseker B. Unconfident / Ukungaqiniseki / Onseker C. Confident / Ukuqiniseka / Selfversekerd D. Very confident / Ulkuqiniseka kakhulu / Baie selfversekerd
13.	Do you feel you need to improve your level of knowledge of HIV and AIDS? Yes = 1 No = 0 Uziva ufuna ukuphucula umgangatho wolwazi lwakho lweHIV ne AIDS/ noGawulayo? Ewe = 1 Hayi = 0 Voel u dat u u kennis oor HIV en AIDS moet verbeter? Ja = 1 Nee = 0	
14.	Please explain your answer to Question 15. Nceda chaza impendulo yakho kumbuzo 15. Verduidelik asseblief u antwoord op Vraag 15.	
15.	Do you feel you need more training in home-based care skills? Yes = 1 No = 0 Uziva ufuna uqeqesho oluthe kratya lwezakhono zokunonelela / zokukhathalela abantu ekhaya? Ewe = 1 Hayi = 0 Voel u dat u meer opleiding in tuisversorgingsvaardighede nodig het? Ja = 1 Nee = 0	
16.	Please explain your answer to Question 17. Nceda chaza impendulo yakho kumbuzo 17. Verduidelik asseblief u antwoord op Vraag 17.	
17.	Have you been trained to do the following? / Ukhe waqeqeshelwa oku kulandelayo? / Het u opleiding ontvang om die volgende te doen? **Have you been trained to: / Ukuqeqeshelwe uku: / Is us opgelei om:**	*Yes = 1 No = 0* **Ewe = 1 Hayi = 0** **Ja = 1 Nee = 0**
A.	Lift a client / Phakamisa umntu / 'n Kliënt op te lig	
B.	Help a client out of bed / Nceda umguli ukuphakama emandlalweni / 'n Kliënt uit die bed te lig	
C.	Teach motion exercises / Fundisa yentshukumo / Bewegingsoefeninge te onderrig	
D.	Shave a male client / Tsheva umguli oyindoda / 'n Manlike kliënt te skeer	
E.	Feed a client / Tyisa umguli / 'n Kliënt te voer	
F.	Give advice about mouth care / Nika icebiso ngokukhathalela umlomo / Raad te gee oor mondhigiëne	
G.	Measure intake/output / Linganisa okungenayo/okuphumayo / Insette en uitsette te meet	
H.	Teach breathing exercises / Fundisa imithambo yokuphefumlisa / Asemhalingsoefeninge te onderrig	
I.	Assist a client who is having oxygen therapy / Ncedisa umguli ononcedo lomongomoya / 'n Kliënt wat suurstof terapie kry te ondersteun	
J.	Assist a client who is coughing / Nceda umguli okhohlelayo / 'n Kliënt wat hoes te ondersteun	
K.	Assist a client who is vomiting / Nceda umguli okhuphayo/ ohlanzayo / 'n Kliënt wat vomeer te ondersteun	
L.	Collect sputum / Qokelela / Speeksel te vang /	
M.	Take temperature / Thatha ithempritsha / Temperatuur te neem	
N.	Take pulse / Thatha iphalsi / Polsslag te neem	
O.	Put a client in the recovery position / Beka umguli ngendlela yaxa echacha / 'n Kliënt in die herstelposisie te sit	
P.	Put on and take off gloves / Beka uze ukhulule iiglavu / Handskoene aan en uit te trek	
Q.	Make beds / Yandlula / Beddens te maak	
R.	Position your client on the bed / Beka kakuhle umguli wakho kumandlalo / U kliënt op die bed te posisioneer	
S.	Use a wheelchair / Sebenzisa isitulo esiqhutywayo / 'n Rolstoel te gebruik	
T.	Give pressure care / Nika uxinzelelo lononelelo/ lwenkathalo / Druksorg te gee	
U.	Wash hair in bed / Hlamba iinwele kumandlalo / Hare in die bed te was	
V.	Give hand and foot care / Nika unonelelo/ inkathalo yesandla nonyawo / Hand- en voetsorg te gee	
W.	Give a bedpan / Nika ipani yomandlalo/ itsheyimba / 'n Bedpan te gee	
X.	Give catheter care / Nika unonelelo lwekhathetha / Katetersorg te gee	
Y.	Test urine / Umchamo wovavanyo / Urine te toets	
Z.	Give medicines / Nika amayeza / Medisyne te gee	
AA.	Help a client who is choking / Nceda umguli ngubani utshowukhayo / 'n PLHA wat stik te help	
AB.	Dispose of sputum / Ukukhupha isikhohlela / Van speeksel ontslae te raak	
AC.	Give tepid sponging / Sula ngesponji esidikidiki / Louwarm afsponsing te doen	
AD.	Stop bleeding / Yeka ukopha / Bloeding te stop	
AE.	Other (specify) / Okunye (chaza) / Ander (spesifiseer) ____	

Section D – Clients
Icandelo – Abagulayo
Afdeling D – Kliënte

1.	How many clients have you had altogether since you started working as a VCG? Bangaphi abagulayo obukhe wanabo bephelele ukususela ekuqaleni kokusebenza njenge VCG? Hoeveel kliënte het u al gehad vandat u as 'n TV begin werk het?	
2.	How many clients have you cared for in the last month? Bangaphi abagulayo oye wabakhathalela kwinyanga ephelileyo? Hoeveel kliënte het u in die laaste maand voor gesorg?	
3.	How many clients have you cared for over the past 6 months? Bangaphi abagulayo okhe wabakhathalela kangaphezu kweenyanga ezi – 6? Hoeveel kliënte het u in die laaste 6 maande versorg?	
4.	How many clients do you care for in one day (on average)? Bangaphi abagulayo obakhathalelayo ngosuku? Hoeveel kliënte versorg u per dag?	
5.	How many days per month do you visit a single client? Zingaphi iintsuku ngenyanga otyelela umguli ngamnye? Hoeveel dae per maand besoek u 'n enkele kliënt?	day(s) per month
6.	Do you visit some clients more than others? Yes = 1 No = 0 Uyabatyelela abaguli abathile ngaphezu kwabanye? Besoek u sommige kliënte meer dikwels as ander?	
7.	If yes, why do you visit some clients more than others? Ukuba kunjalo, kutheni utyelela abathile ngaphezu kwabathile? Indien ja, hoekom besoek u sommige kliënte meer dikwels as ander?	
8.	How many of your adult clients are **male**? (Older than 19) Bangaphi kubaguli abadala bakho abangamadoda? (Ababudala bungaphezu kune-19) Hoeveel van u volwasse kliënte is manlik? (ouer as 19)	
9.	How many of your adult clients are **female**? (Older than 19) Bangaphi kubaguli abadala bakho ababhinqileyo? (Ababudala bungaphezu kune-19) Hoeveel van u volwasse kliënte is vroulik? (ouer as 19)	
10.	How many of your clients are **babies**? (2 years or younger) Bangaphi abaguli bakho abaziintsana (Iminyaka emi-2 nangaphantsi) Hoeveel van u kliënte is babas? (2 jaar of jonger)	
11.	How many of your clients are **children**? (Older than 2 years but 12 or younger) Bangaphi abaguli bakho abangabantwana? (Abadala kuneminyaka emi-2 kodwa ibe -12 okanye ngaphantsi) Hoeveel van u kliënte is kinders? (ouer as 2 jaar maar 19 of jonger)	
12.	How many of your clients are **teenagers**? (Older than 12 years but 19 or younger) Bangaphi abaguli abalulutsha? (Abangaphezu kwe-12 kodwa ibe-19 okanye ngaphantsi) Hoeveel van u kliënte is tieners? (ouer as 12 jaar maar 19 of jonger)	
13.	How many of your clients are your **family members**? Bangaphi abaguli abangamalungu osapho? Hoeveel van u kliënte is lede van u familie?	
14.	How many of your clients do you care for **in your own house**? Bangaphi abaguli obakhathaleleyo endlwini yakho? Hoeveel van u kliënte versorg u in u eie huis?	
15.	How many of your clients are **neighbours to you**? Bangaphi abaguli abangabamelwane bakho? Hoeveel van u kliënte is bure van u?	
16.	How many of your clients have passed away since you started work as a VCG? Bangaphi abaguli ababhubhileyo ukususela ukuqala kwakho ukusebenza njengeVCG? Hoeveel van u kliënte het al gesterf vandat u as TV begin werk het?	
17.	How many of your clients have passed away since you've been at this agency? Bangaphi abaguli ababhubhayo ukususela oko waba kule arhente? Hoeveel van u kliënte het al gesterf vandat u by die agentskap begin werk het?	
18.	How many of your clients have disclosed their HIV status to you?	

	Bangaphi abaguli bakho abazixele imeko yabo yeHIV? Hoeveel van u kliënte het hul HIV-status aan u meegedeel?	
19.	How many of your clients are on ARVs? Bangaphi abaguli bakho abafumana ii –ARV? Hoeveel van u kliënte is op ARVs?	
20.	How many of your clients have been for VCT (i.e. they know their HIV-status)? Bangaphi abaguli abebefumene iVCT(bayayazi imeko yabo ye-HIV)? Hoeveel van u kliënte het al vir vrywillige MIV toetse gegaan (dws hulle ken hulle HIV-status)?	
21.	How many of your clients are bedridden? Bangaphi abaguli abagula belele? Hoeveel van u kliënte is bedlêend?	
22.	How many of your clients are ambulatory (able to walk)? Bangaphi abaguli abahanjiswa ngenqwelo yezigulane(abanokuhamba)? Hoeveel van u kliënte kan loop?	
23.	How many of your adult clients are working full time? Bangaphi abaguli abadala abasebenza isigxina? Hoeveel van u volwasse kliënte werk voltyds?	
24.	How many of your adult clients are working part time? Bangaphi abaguli abadala abasebenza okwexeshana? Hoeveel van u volwasse kliënte werk deeltyds?	
25.	How many of your adult clients are unemployed? Bangaphi abaguli abadala ongaqeshwanga? Hoeveel van u volwasse kliënte is werkloos?	
26.	What basic supplies do you provide for your clients? (Circle **ALL** relevant letter(s)) Zeziphi iimfuno ezisisiseko sempilo obanika zona abaguli bakho? (Chwetheza ibhokisi eyiyo) Watter basiese voorrade verskaf u aan u kliënte? (merk al die relevante opsies)	A. Food / ukutya / Kos B. Blankets / Iingubo / Komberse C. Clothes / Impahla / Klere D. Baby milk/formula / Ubisi / Babamelk/Melkpoeier E. Equipment at home (e.g. mattress; catheter) / Izixhobo ekhaya (umz. Umatrasi; ikhathethi) / Toerusting by die huis (bv. Matras, kateter) F. Gauze / Igozi / Gaasdoek G. Bandages / Amabande / Verbande H. Gloves / Iiglavu / izingxobo zezandla / Handskoene I. Tea Tree Oil / I-oyile yomthi weti / "Tea tree" olie J. Aqueous Cream / Amafutha e- akhwasi / Aqueous room K. Other (specify) / Okunye (chaza) / Ander (spesifiseer) _______________________
27.	Do you give your clients medicine for their pain? Yes = 1 No = 0 Uyabanika abaguli amayeza eentlungu? Ewe = 1 Hayi = 0 Verskaf u medisyne vir pyn aan u kliënte? Ja = 1 Nee = 0	
28.	If yes, what medicines do you give your clients to help remove the pain? Ukuba kunjalo, ngawaphi amayeza owanika abaguli okunyanga iintlungu? Indien ja, watter medisyne verskaf u aan u kliënte om die pyn weg te neem?	
29.	How many of your clients are on medical aid? Bangaphi abaguli abakwimedikhali? Hoeveel van u kliënte het 'n mediese fonds?	
30.	Do you know about universal precautions? (U.P.)? Yes = 1 No = 0 Unolwazi ngamanyathelo okulumkela kuluntu jikelele? (U.P.) Ewe = 1 Hayi = 0 Weet u van universele voorsorgmaatreëls? Ja = 1 Nee = 0	
31.	If yes, describe in your own words what U.P. are? Ukuba kunjalo, chaza ngawakho amazwi ukuba yintoni i_U.P.? Indien ja, beskryf in u eie woorde wat 'n universele voorsorgmaatreël is?	
32.	What have you taught your clients about health care? Ubafundise ntoni abaguli bakho? Wat het u, u kliënte geleer?	

33.	Do you provide your clients with spiritual support? Yes = 1 No = 0 Uyabaxhasa abaguli bakho ngokomoya? Ewe = 1 Hayi = 0 Gee u, u kliënte geestelike ondersteuning? Ja = 1 Nee = 0	
34.	If yes, how do you provide spiritual support to your clients? Ubaxhasa njani abaguli bakho ngokomoya? Indien ja, hoe gee u, u kliënte geestelike ondersteuning?	
35.	Are there any factors that prevent you from providing quality care and support to your clients and their families? Yes = 1 No = 0 Ingaba zikho izinto ezikuthintela ungabi nakho ukunika inkathalo eyiyo nokuxhasa abaguli bakho neentsapho zabo? Ewe = 1 Hayi = 0 Is daar enige ander faktore wat u verhoed om kwaliteit sorg en ondersteuning aan u kliënte en hulle families te gee? Ja = 1 Nee = 0	
36.	Please explain your answer to Question 35: Nceda uchaze impendulo yakho kumbuzo 35: Verduidelik asseblief u antwoord op vraag 35?	
37.	Have you ever been asked by a client to disclose his/her HIV status to his/her family? Yes = 1 No = 0 Awuzange ukhe ucelwe ngumguli ukuba uxele imeko yakhe kusapho lwakhe? Ewe = 1 Hayi = 0 Is u al ooit deur 'n kliënt gevra om sy/haar HIV-status aan sy/haar familie mee te deel? Ja = 1 Nee = 0	
38.	Have you ever witnessed conflict between a client and his/her family because of his/her HIV status? Yes = 1 No = 0 Wawukhe wayingqina ingxabano phakathi komguli nosapho lwakhe ngenxa yemeko yeHIV? Ewe = 1 Hayi = 0 Het u al ooit konflik agv sy/haar HIV-status tussen 'n kliënt en sy/haar familie gesien? Ja = 1 Nee = 0	
39.	If yes, please describe the reasons for the conflict: Ukuba kunjalo, chaza isizathu sengxabano: Indien ja, verduidelik asseblief die redes vir die konflik	
40.	Have you ever been asked to assist with making peace between family members in such a conflict? Yes = 1 No = 0 Wakha wacelwa ukuba ube ngumxolelanisi phakathi kwengxabano yamalungu osapho? Ewe = 1 Hayi = 0 Is u al ooit gevra om vrede tussen die gesinslede te maak in die geval van so 'n konflik? Ja = 1 Nee 0	
41.	If yes, please describe how you handled the situation: Ukuba kunjalo chaza indlela owayilawula ngayo loo meko: Indien ja, beskryf asseblief hoe u die situasie hanteer het	
42.	Have you ever experienced conflict between yourself and a family member of a client? Yes = 1 No = 0 Wakha wabandakanyeka kwingxabano nelungu losapho lomguli? Het u al ooit konflik tussen uself en 'n familielid ondervind?	
43.	If yes, please describe how you handled the situation: Ukuba kunjalo, nceda ucacise indlela owayilawula ngayo loo meko: Indien ja, beskryf asseblief hoe u die situasie hanteer het:	
44.	Have you ever experienced conflict between yourself and a client? Yes = 1 No = 0 Wakha wanayo ingxabano kunye nomguli? Ewe = 1 Hayi = 0 Het u al ooit konflik tussen uself en 'n kliënt ondervind? Ja = 1 Nee = 0	
45.	If yes, please describe how you handled the situation: Ukuba kunjalo nceda uchaze indlela owayilawula ngayo lo meko? Indien ja, beskryf asseblief hoe u die situasie hanteer het:	

Section E – Volunteer Caregiver (VCG)
ICandelo E – Abongi abangamaVolontiya (VCG)
Afdeling E – Vrywillige Versorger (VV)

1.	How do you rate the clinic / hospital nurses respect for you as a VCG? (Circle relevant letter) Ungayilinganisa njani imbeko oyinikwa ngabongikazi baseKlinikhi nabo basesibhedlele? Hoe evalueer u die kliniek/hospital verpleegsters se respek vir u as 'n VV?	A. Very disrespectful / Abakuhloniphi kwaphela / Baie onbeleef B. Disrespectful / Abakuhloniphi / Onbeleef C. Respectful / Bayakuhlonipha / Beleef D. Very respectful / Bakuhlonipha kakhulu / Baie beleef	
2.	Please explain your answer to Question 1: Nceda uchaze impedulo yakho engentla kumbuzo 1: Verduidelik asseblief u antwoord op nommer 1:		
3.	Do you ever ask the clinic / hospital nurses for advice? Yes = 1 No = 0 Ukhe ucele ingcebiso kubongikazi baseklinikhi /basesibhedlele? Ewe = 1 Hayi = 0 Vra u ooit die kliniek/hospitaalverpleegsters vir advies? Ja = 1 Nee = 0		
4.	If yes, what kind of advice have you asked for? Ukuba kunjalo, ngcebiso ni owakhe wayicela? Indien ja, watter soort advies het u al voor gevra?		
5.	How approachable are the nurses at the clinic and hospital with regard to asking for advice? (Circle relevant letter) Bafikeleleka kanganani abongikazi baseklinikhi nasesibhedlele malunga nokucelwa ingcebiso Hoe toeganklik is die verpleegsters by die kliniek en by die hospital wanneer u hulle om advies vra?	A. Very unapproachable / abayafikeleleka kwaphela / Baie ontoeganklik B. Unapproachable / Abafikeleleki / Ontoeganklik C. Approachable / Bayafikeleleka / Toeganklik D. Very approachable / Bafikeleleka kakhulu / Baie toeganklik	
6.	Please give an example to explain your answer. Nceda unike umzekelo ukucacisa impendulo yakho. Gee asseblief 'n voorbeeld om u antwoord te verduidelik		
7.	Do you feel that you need more spiritual support in your work as a VCG? Yes = 1 No = 0 Ucinga ukuba udinga inkcaso yasemphefumlweni kumsebenzi wakho njenge VCG? Ewe = 1 Hayi = 0 Voel u dat u as VV meer geestelike ondersteuning nodig het? Ja = 1 Nee = 0		
8.	Please explain your answer to Question 7: Nceda uchaze impendulo yakho ekumbuzo 7: Verduidelik asseblief u antwoord op vraag 7:		
9.	How often do you meet with your fellow VCGs away from meetings? Nidibana kangakanani nabalingane bakho abaziVCG ngaphandle komsebenzi? Hoe dikwels ontmoet u, u mede VVs op 'n vriendskaplike basis?		Day(s) per week or day(s) per month
10.	Do you help each other with your problems? Yes = 1 No = 0 Niyancedana kwiingxaki zenu? Ewe = 1 Hayi = 0 Help julle mekaar met julle probleme? Ja = 1 Nee = 0		
11.	Please explain your answer to Question 10: Nceda uchaze impendulo yakho ekumbuzo 10: Verduidelik asseblief u antwoord op vraag 10:		
12.	Have you ever found it difficult to carry out your work as a caregiver? Yes = 1 No = 0 Wakha wava kunzima ukwenza umsebenzi wakho njengomongi? Ewe = 1 Hayi = 0		

	Het u dit al ooit moeilik gevind om u werk as versorger uit te voer? Ja = 1 Nee = 0	
13.	Please explain your answer to Question 12: Nceda uchaze impendulo yakho ekumbuzo 12: Verduidelik asseblief u antwoord op vraag 12:	
14.	Have your clients ever complained to you about how you care for them? Yes = 1 No = 0 Ingaba abaguli bakho bakha bakhalaza ngendlela obonga ngayo? Ewe = 1 Hayi = 0 Het u kliënte al ooit gekla oor hoe u vir hulle sorg? Ja = 1 Nee = 0	
15.	Please explain your answer to Question 14: Nceda uchaze impendulo yakho ekumbuzo 14. Verduidelik asseblief u antwoord op vraag 14:	
16.	Does your family encourage you in your work as a VCG? Yes = 1 No = 0 Ingaba usapho lwakho luyakukhuthaza kumsebenzi wakho wokuba yiVCG? Ewe = 1 Hayi = 0 Het u familie u in u werk as VV aangemoedig? Ja = 1 Nee = 0	
17.	Please explain your answer to Question 16: Nceda uchaze impendulo yakho ekumbuzo 16: Verduidelik asseblief u antwoord op vraag 16:	
18.	What keeps you motivated as a VCG? Yintoni ekukhuthazayo ekubeni yiVCG? Wat hou u as ‘n VV gemotiveerd?	
19.	What discourages you as a VCG? Yintoni ekutyhafisayo ekubeni yi VCG? Wat maak u as VV mismoedig?	
20.	Does your community encourage you in your work as a VCG? Yes = 1 No = 0 Ingaba abahlali bayakukhuthaza kumsebenzi wakho wokuba yiVCG? Ewe = 1 Hayi = 0 Bemoedig u gemeenskap u in u werk as VV aan? Ja = 1 Nee = 0	
21.	Please explain your answer to Question 20: Nceda uchaze impendulo yakho ekumbuzo 20: Verduidelik asseblief u antwoord op vraag 20:	
22.	Many VCGs say that their work is emotionally draining; do you ever experience such feelings? Yes = 1 No = 0 IiVCG ezininzi zithi umsebenzi wazo ukuphelisa uvakalelo; ingaba ukhe uve nayo le mvakalelo? Ewe = 1 Hayi = 0 Baie VVs sê dat hulle werk emosioneel dreinerend is; voel u ook so? Ja = 1 Nee = 0	
23.	Please explain your answer to Question 22: Nceda uchaze impendulo yakho ekumbuzo 22. Verduidelik asseblief u antwoord op vraag 22:	
24.	Do you receive any psychological/emotional support from your CHBC Agency? Yes = 1 No = 0 Ingaba uyayifumana inkxaso ngokwasengqondweni /noluvo kwiArhente yakho? Ewe = 1 Hayi = 0 Ontvang u enige sielikundige/emosionele ondersteuning van die agentskap? Ja = 1 Nee = 0	
25.	Please explain your answer to Question 24: Nceda uchaze impendulo yakho ekumbuzo 24: Verduidelik asseblief u antwoord op vraag 24:	

26.	What kind of psychological / emotional support do you receive away from the CHBC Agency? Please explain. Loluphi uhlobo lwenkxaso ngokwasengqondweni/luvo olufumana ngaphandle kweArhente ye CHBC? Nceda uchaze. Watter tipe sielkundige/emosionele ondersteuning ontvang u van buite die agentskap? Verduidelik asseblief.	
27.	Are there any other issues that you would like to raise or discuss relating to your experiences as a VCG? Ingaba ikhona eminye imiba onqwenela ukuyiphakamisa okanye ukuyixoxa engqamene namava akho njengeVCG? Is daar enige ander sake in verband met u ondervindings as 'n VV wat u graag wil ophaal of bespreek?	
28.	How would you describe a typical day working as a VCG in your CHBC agency, starting from the time you leave home in the morning until the time you get back in the evening? Ungayichaza injani imini yakho njengomsebenzi oyiVCG kule arhente iCHBC ukusukela ngexesha lakusasa lokuphangela kude kuye kwixesha lokubuya kwakho emsebenzini? Hoe sal u 'n tipiese werkende dag van 'n VV in u agentskap beskryf. Begin by jou vertrek van die huis af in die oggend totdat u terugkeer huis toe in die aand?	

Section F: Monitoring and Evaluation
ICandelo F: uLolongo noHlolo
Afdeling F: Monitering en Evaluering

1.	Has your work as a VCG ever been evaluated? Yes = 1 No = 0 Umsebenzi wakho njengeVCG wakha wahlolwa? Ewe = 1 Hayi = 0 Was u werk as VV al ooit geëvalueer? Ja = 1 Nee = 0		
2.	If yes, when last were you evaluated? Year(s) and/or Month(s) ago Ukuba kunjalo; wagqityelwa nini ukuhlolwa? Unyaka/iminyaka okanye iinyanga ezidlulileyo Indien ja, wanneer laas was u geëvalueer? Jaar/Jare en of maand€ gelede	Years	Months
3.	Who did the evaluation? Ngubani owakuhlolayo? Wie het die evaluering gedoen?		
4.	Did you receive feedback? Yes = 1 No = 0 Wayifumana ingxelo? Ewe = 1 Hayi = 0 Het u terugvoer ontvang? Ja = 1 Nee = 0		
5.	Please explain what took place during the evaluation. Chaza ukuba kwenzeka ntoni ngexesha lohlolo. Verduidelik asseblief wat gedurende die evaluering plaasgevind het:		

Section G: Transport and Communication
Icandelo G: UThutho noNxibelelwano
Afdeling G: Vervoer en Kommunikasie

1.	Do you own a car? Yes = 1 No = 0 Unayo imoto? Besit u, u eie motor?	
2.	Do you have access to a family member or friend's car? Yes = 1 No = 0 Uyakwazi ukufumana imoto yelungu losapho lwakho okanye eyesihlobo sakho? Het u toegang tot 'n familielid of vriend se motor?	
3.	How many clients live too far away from your house, for you to walk to visit them? Bangaphi abaguli abahlala kude kwikhaya lakho ekunzima ukuba ubahambele ngenyawo? Hoeveel kliënte woon te ver van u huis af vir u om na hulle te voet te besoek?	
4.	Do you help transport your clients to the clinic or hospital? Yes = 1 No = 0 Uyabanceda ukubakhwelise abaguli ukuya eklinikhi okanye esibhedlele? Ewe = 1 Hayi = 0 Help u, u kliënte met vervoer na en van die kliniek of hospitaal? Ja = 1 Nee = 0	
5.	If yes, when you take your client to the clinic or hospital, do you take (Circle relevant letter): Ukuba uthi ewe, xa ubasa eklinikhi okanye esibhedlele usebenzisa: Indien ja, wanneer u u kliënt na die kliniek of hospitaal vervoer, neem u:	A. Your car / Imoto yakho / U motor B. A taxi / iTeksi / 'n Taxi C. A bus / iBhasi / 'n Bus D. A friend's car / Imoto yesihlobo sakho / 'n Vriend se motor E. Other (specify) / Enye into (cacisa) / Ander (spesifiseer) ____________________
6.	Do you ever pay taxi fare or bus fare for your client when you accompany them? Yes = 1 No = 0 Uyayibhatala iteksi okanye ibhasi xa ukhapha umguli? Ewe = 1 Hayi = 0 Betaal u ooit taxigeld of busgeld vir u kliënte wanneer u hulle vergesel? Ja = 1 Nee = 0	
7.	Do you receive a petrol/taxi stipend from your agency? Yes = 1 No = 0 Uyavuzwa ngepetroli/ ngemali yeteksi liqumrhu lakho? Ewe = 1 Hayi = 0 Ontvang u 'n petrol/taxi stipendium van u agentskap? Ja = 1 Nee = 0	
8.	Do you have your own house telephone? Yes = 1 No = 0 Unayo ifowuni yakho ekhaya? Ewe = 1 Hayi = 0 Besit u, u eie huistelefoon? Ja = 1 Nee = 0	
9.	Do you have your own cell phone? Yes = 1 No = 0 Unayo iselufowuni yakho? Ewe = 1 Hayi = 0 Besit u, u eie selfoon? Ja = 1 Nee = 0	
10.	Do your clients contact you on your telephone or cell phone? Yes = 1 No = 0 Ingaba abaguli bakho bayakufowunela efowunini okanye kwiselufowuni? Ewe = 1 Hayi = 0 Kontak u kliënte u op u telefoon of selfoon? Ja = 1 Nee = 0	
11.	How many times per day do you get calls from clients? (per day) Abaguli bakufowunela kangaphi ngosuku? Hoeveel keer per dag ontvang u oproepe van u kliënte?	
12.	Do you contact your clients by telephone or cell phone? Yes = 1 No = 0 Uyabafowunela wena abagulu ngefowuni okanye ngeselufowuni? Ewe = 1 Hayi = 0 Kontak u, u kliënte per telefoon of selfoon? Ja = 1 Nee = 0	
13.	Give some examples why you need to contact your clients by telephone or cell phone: Nika imizekelo apho kuye kufuneke ukuba ufowunele abaguli ngefowuni okanye ngeselufowuni: Gee 'n paar voorbeelde van waarom u nodig het om u kliënte per telefoon of selfoon te kontak:	

Section H – VCG Supervisor
Icandelo H – Umphathi weVCG
Afdeling H – VV Toesighouer

1.	How many days a month/year does your supervisor visit your clients? Day(s) per month or day(s) per year / Umphathi wakho ubahambela kangaphi ngenyanga/ngonyaka abaguli bakho? Usuku/iintsuku ngenyanga okanye ngonyaka / Hoeveel dae per maand/jaar besoek u toesighouer u kliënte? Dag/dae per maand of dag/dae per jaar	Day(s) per month	Day(s) per year
2.	What would you like your supervisor to do for you that she/he doesn't do for you at present? Yintoni onqwenela ukuba umphathi wakho akwenzele yona, into angayenziyo? Wat sou u graag wil hê moet die toesighouer vir u doen wat hy/sy op die oomblik nie doen nie?		
3.	What would you like your supervisor not to do? Yintoni onqwenela ukuba umphathi wakho angayenzi? Wat moet die toesighouer nie doen nie?		
4.	How many days a month or year, do you meet with your supervisor in a group? Day(s) per month or day(s) per year / Nidibana kangaphi ngenyanga okanye ngonyaka nomphathi wakho niliqela? Usuku/iintsuku ngenyanga okanye ngonyaka / Hoeveel dae per maand of jaar ontmoet u u toesighouer in 'n groep? Dag/dae per maand of dag/dae per jaar	Day(s) per month	Day(s) per year
5.	How many days a month or year, do you meet with your supervisor one-on-one? Day(s) per month or day(s) per year / Nidibana kangaphi ngenyanga okanye ngonyaka wena nomphathi wakho kuphela? Usuku/iintsuku ngenyanga okanye ngonyaka / Hoeveel dae per maand of jaar ontmoet u u toesighouer persoonlik? Dag/dae per maand of dag/dae per jaar	Day(s) per month	Day(s) per year
6.	Are you able to meet with your supervisor outside of the regular meetings? Yes = 1 No = 0 Is dit vir u moontlik om u toesighouer buiten die gereelde vergaderings te ontmoet? Ja = 1 Nee = 1		
7.	Do you feel comfortable talking to your supervisor? Yes = 1 No = 0 Uziva ukhululekile ukuthetha nomphathi wakho? Ewe = 1 Hayi = 0 Voel u gemaklik om met u toesighouer te praat? Ja = 1 Nee 0		
8.	Please explain your answer to Question 7: Cacisa impendulo yakho engentla Verduidelik asseblief u antwoord op vraag 7:		
9.	If you answered yes to Question 7, what are some of the issues you discuss with your supervisor? Ukuba impendulo yakho ngu- ewe ku -7 nixoxa ntoni nomphathi wakho? Indien u ja op vraag 7 geantwoord het, wat is sommige van die sake wat u met u toesighouer bespreek?		
10.	Can your supervisor speak your language? Yes = 1 No = 0 Umphathi wakho uyakwazi ukuthetha ulwimi lwakho? Ewe = 1 Hayi = 0 Kan u toesighouer u taal praat? Ja = 1 Nee = 0		
11.	Do you go to your supervisor for counselling? Yes = 1 No = 0 Uyaya kumphathi wakho ukuze akucebise? Ewe = 1 Hayi = 0 Gaan u na u toesighouer vir berading? Ja = 1 Nee = 0		
12.	Who do you go to for counselling besides your supervisor? Ngubani omnye oya kuye ukuze akucebise ngaphandle komphathi wakho? Na wie toe gaan u vir berading behalwe u toesighouer?		
13.	Do any other supervisors or managers from your CHBC agency visit your clients? Yes = 1 No = 0 Ingaba ukhona omnye umphathi okanye umanejala wequmrhu leCHBC ohambela abaguli bakho? Ewe = 1 Hayi = 0 Besoek enige ander toesighouers of bestuurders van u agentskap u kliënte? Ja = 1 Nee = 0		
14.	Is there anything else that you think you could tell me about your supervisor? Ikhona enye into ofuna ukundixelela ngayo malunga nomphathi wakho? Is daar enigiets wat u graag vir my van u toesighouer wil vertel?		

Section I – Willingness to Care
Icandelo 1 – Ukuzinikela ekongeni
Afdeling I – Gewilligheid om te versorg

1 = completely unwilling
2 = somewhat unwilling
3 = not sure
4 = somewhat willing
5 = completely willing

1 =Ukungazimiseli kwaphela
2 = ukungazimiseli ncam
3 = ukungaqiniseki
4 = ungazimiseli ncam
5 = ukuzimisela ngokupheleleyo

1 = heeltemal onwillig
2 = ietwat onwillig
3 = nie seker nie
4 = effens gewillig
5 = heeltemal gewillig

	How willing are you to? / Uzimisele kangakanani? / Hoe gewillig is u om?	**1**	**2**	**3**	**4**	**5**
A.	Comfort your client when he/she is upset / Ukuthuthuzela umguli wakho xa ekhathazekile / ‘n Kliënt te troos wanneer hy/sy ontsteld is					
B.	Take your client to the doctor / Ukusa umguli wakho kwagqirha / U kliënt dokter toe te vat					
C.	Bring home groceries for your client / Ukuphathela umguli wakho ukutya / Kruideniersware vir u kliënt huis toe te neem					
D.	Help pay for your client’s medicine / Ukunceda ubhatala emayeza omguli wakho / Vir u kliënt se medisyne te betaal					
E.	Prepare meals for your client / Ukulungisela umguli wakho ukutya / Maaltye vir u kliënt voor te berei					
F.	Do housework for your client / Ukucocela indlu umguli wakho / Skoonmaak werk vir u kliënt te doen					
G.	Do your client’s laundry / Ukuhlambela umguli wakho / U kliënt se wasgoed te doen					
H.	Help pay for your client’s food or housing / Ukubhatalela umguli ukutya okanye indlu / Vir u kliënt se kos of behuising te help betaal					
I.	Have your client live in your home / Ukugcina umguli endlwini yakho / U kliënt in u huis te huisves					
J.	Help your client take medicine / Ukumncedisa umguli asele amayeza / U kliënt te help om medisyne te neem					
K.	Change your client’s dirty bed sheets / Ukutshintsha amashiti amdaka omguli wakho / U kliënt se vuil beddegoed om te ruil					
L.	Help your client take a bath / Ukunceda umguli wakho ahlambe / U kliënt te help om te bad					
M.	Clean up after your client who lost bowel or bladder control / Ukucoca emva kokuba umguli wakho eshiywe ngumchamo okanye ezingcolisele / Skoon te maak nadat u kliënt beheer oor sy/haar blaas of derm verloor het					
N.	Help your client eat a meal / Ukunceda umguli wakho atye / U kliënt te help om te eet					
O.	Clean up when your client has thrown up / Ukucoca emva kokuba umguli wakho egabhile / Skoon te maak nadat u kliënt opgegooi het					
P.	Turn or move your client in and out of bed / Ukuguqula nokuphakamisa umguli wakho ebhedini / U kliënt om te draai of te help om in en uit die bed te kom					
Q.	Change dressings on your client’s sores / Ukutshintsha amabhandeyiji kwizilonda zomguli wakho / Skoon verbande op u kliënt se seerplekke te sit					
R.	Help your client in the bathroom / Ukumncedisa umguli wakho kwindlu yangasese / U kliënt in die badkamer te help					

Section J – Experience as a VCG
Icandelo J – Amava njengeVCG
Afdeling J – Onderving as VV

1.	How often do you feel the following with regard to your work as a VCG? Tick the relevant box. Mangaphi amaxesha othi uzive ngolu hlobo lulandelayo ngomsebenzi wakho njenge VCG? Korekisha ibhokisi efanelekileyo. Hoe dikwels voel u die volgende met betrekking tot u werk as VV? Merk die toepaslike opsie			
	How often do you feel? **Uziva kangakanani ngolu hlobo?** **Hoe dikwels voel u?**	**Not often** **Amaxa ambalwa** **Nie dikwels nie**	**Often** **Rhoqo** **Dikwels**	**Very often** **Amaxesha onke** **Baie dikwels**
A.	Emotionally drained from your work Usengekile ngokwasemphefumlweni Emosioneel gedreineer as gevolg van u werk			
B.	You could easily understand how your clients felt about things Ukuba uyiqonda lula indlela abaguli baziva ngayo ngezinto Dat u goed kan verstaan hoe u kliënte oor sekere dinge voel			
C.	You could deal very effectively with the problems of your clients Unakho ukumelana neengxaki zabaguli bakho Dat u u kliënte se probleem baie doeltreffend sal kan hanteer			
D.	You were positively influencing other people's lives through your work Unefuthe elakhayo kubomi babanye abantu ngomsebenzi wakho Dat u deur u werk ander mense se lewens positief beïnvloed			
E.	That your work as a VCG was hardening you emotionally Umsebenzi wakho njengeVCG uyakomeleza emphefumlweni Dat u werk as VV u emosioneel hard gemaak het			
F.	Frustrated with your work as a VCG Uxakanisekile ngumsebenzi wakho Gefrustreerd met u werk as VV			
G.	That you didn't really care what happened to some clients Akukhathali malunga nokwenzeka kwabanye abaguli Dat u nie regtig omgee wat met u kliënte gebeur nie			
H.	That you could easily create a relaxed atmosphere with your clients Unakho ukwenza umoya woxolo neziguli zakho Dat u maklik 'n ontspanne atmosfeer met u kliënte kan skep			
I.	Exhilarated after working closely with your clients Ugcobile emva kokusebenza ngokusondeleyo nabaguli bakho Dat u opgewek voel nadat u nou saam met u kliënte gewerk het			
J.	That you had accomplished many worthwhile things in your job Uphumeze izinto ezininzi ezinexabiso kumsebenzi wakho Dat u baie waardevolle dinge in u werk bereik het			
K.	That you dealt with emotional problems very calmly Uziphathe ngokuzolileyo iingxaki zemvakalelo Dat u emosionele probleme baie kalm hanteer het			
L.	That your clients blamed you for some of their problems Abaguli bakho maxa wambi bayakutyhola ngezinye ingxaki zabo Dat u kliënte u vir sommige van hulle probleme blameer			

	Record time of interview **end**: Hour / Minute (e.g. 9.30, or 14.25) Bhala ixhesha ephele ngalo-impendulo yemibuzo: Iyure / Imizuzu Teken die eindtyd van die onderhoud aan: Uur / Minute	Hour	Minute

APPENDIX E:

Client participants:

Subject information sheets, consent forms and questionnaire

APPENDIX E

Subject Information Sheet for Client Participants

Dear prospective participant,

My name is David Morton. I am a doctoral student in sociology at the Nelson Mandela Metropolitan University (NMMU). As part of my degree, I am conducting a research study on volunteer home-based caregivers.

The main aim of this study is to determine the quality of the care that is provided by volunteer home-based caregivers in the Nelson Mandela Metropolitan Municipality.

I wish to invite you to participate in my study. Please note that your participation is voluntary and that non-participation will have no negative consequences. Should you decide to participate in this study, an interview will be conducted.

Please note that you can withdraw from the study at any time, should you feel that you do not want to continue. If you feel that some of the questions are too personal or if you feel uncomfortable answering them, you have the right to refuse to answer, should you wish to do so. Under no circumstances will any of your responses be shown to anyone other than my two research supervisors and myself. No identifying information will be included in the final report.

To make the interview process easier for me, I would like to make use of a tape/voice recorder, with your permission. However, if you are uncomfortable with this arrangement, I will refrain from using one.

Your participation in this study will help with the monitoring and improvement of the quality of care that is provided by the community home-based care programme. This in turn will benefit the clients of the caregivers.

The outcomes of this research will be sent to all the organisations that took part in the study and from which you can access the study results if you so wish.

Yours faithfully,

David Morton	Professor T.V. Mayekiso
(Researcher) Tel: 076 461 1868	(Research supervisor) Tel: 041-504-2187

CONSENT

I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study.

Participant name printed *Participant signature* *Date*

Name of Person Conducting Informed Consent Discussion/
Witness
(Printed)

Signature of Person Conducting Informed Consent Discussion/ Witness Date

Investigator signature (if different from above) Date

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Witness
(Printed)

Signature of Person Conducting Informed Consent Discussion/ Witness
Date

Investigator signature (if different from above) Date

Project for the Development of a Monitoring / Evaluation Instrument of Volunteer Community Home-based Caregivers

Client Questionnaire:
Iphepha lemibuzo lomxhasi:
Klient Vraelys:

1.	Today's date: (Day/Month/Year) (e.g. 21/03/2009) Umhla: (Umhla/Inyanga?Unyaka) Vandag se datum: (Dag/Maand/Jaar)	Day	Month	Year
2.	Initials of interviewer: Oonobumba begama lowenza udliwano ndlebe: Voorletters van onderhoudvoerder:			
3.	Informed consent obtained? Yes = 1 No = 0 Imvume ifumanekile? Ewe = 1 Hayi = 0 Ingeligte besluit verkry? Ja = 1 Nee = 0			
4.	Record time of interview start: Hour / Minute (e.g. 9.30, or 14.25) Ingxelo ngexesha lokuqala uvavanyo: Iyure / Imizuzu Teken die begintyd van die onderhoud aan: Uur / Minute		Hour	Minute
5.	Which Community Home-Based Care Agency does the client fall under? Ingaba iigosa liphantsi kweliphi lokunika inkxaso abantu? Watter Gemeenskap Tuisgebaseerde Versorgingsagentskap val die klient onder?			
6.	Location of interview: Indawo yodliwano-ndlebe': Plek waar onderhoud plaasvind:			

Section A – Demographics
ICandelo A – Amanani abantu
Afdeling A – Demografie

1.	How long has your VCG been caring for you? / Lixesha elingakanani umongi wakho ekonga? Vir hoe lank sorg u VTV al vir u?	Year(s) and/or Unyaka/iminyaka okanye Jaar/Jare en/of		Month(s) Iiyanga Maande	
2.	Gender Isini Geslag	Male = 1 Indoda = 1 Manlik = 1		Female = 0 Ibhinqa = 0 Vroulik = 0	
3.	How old were you on your last birthday? Ibimingaphi iminyaka yakho ngexesha lomhla wakho wokuzalwa wokugqibela? Hoe oud het u geword op u laaste verjaarsdag?				
4.	What is your marital status? (Circle relevant letter(s)) Ithini imo yakho yomtshato? Wat is u huwelikstatus?	A. Married / Utshatile / Getroud B. Cohabiting / Uyahlalisana / Bly saam C. Divorced / Uqhawule umtshato / Geskei D. Widowed / Ungumhlolo / Wewenaar/Weduwee E. Single/Never married / Akutshatanga / Enkellopend/Nooit getroud nie			
5.	Do you have children? Yes = 1 No = 0 Unabo abantwana? Ewe = 1 Hayi = 0 Het u enige kinders? Ja = 1 Nee = 0				
6.	If yes, how many? Ukuba ngu – ewe bangaphi? Indien ja, hoeveel?				
7.	What is your highest level of education? ((Circle relevant letter(s)) Lithini iqondo eliphakamileyo lemfundo yakho? Wat is u hoogste opvoedingsvlak?	A. No formal education / akunayo imfundo esesikweni / Geen formele opvoeding B. Grade 0 – 3 / iBanga 0 – 3 / Graad 0 – 3 C. Grade 4 – 7 / iBanga 4 - 7 / Graad 4 – 7 D. Grade 8 – 9 / iBanga 8 – 9 / Graad 8 – 9 E. Grade 10 – 12 / iBanga 10 - 12 / Graad 10 – 12 F. Tertiary (specify) / imfundo ephakamileyo (cacisa) / Tersiër (spesifiseer) ________________________________			
8.	What is your population group? (Circle relevant letter(s)) Uloluphi uhlanga? Aan watter bevolkingsgroep behoort u?	A. African / untsundu / Swart B. Coloured / owebala / Kleurling C. Indian / indiya / Indier D. White / umhlophe / Wit E. Don't know / ongaziwayo / Weet nie F. Other (specify) / ezinye (cacisa) / Ander (spesifiseer) _____________________________________			
9.	What is the main language that you speak at home? (Circle relevant letter(s)) Loluphi olona lwimi uluthethayo ekhaya?	A. English / isiNgesi / Engels B. IsiXhosa / isiXhosa / isiXhosa C. Afrikaans / iAfrikans / Afrikaans D. Other (specify) / Ezinye (cacisa) _____________________________________			
10.	To what faith do you belong? (Circle relevant letter(s)) Yeyiphi inkonzo yakho? Aan watter geloof behoort u?	A. None / Andikhonzi / Geen B. Christian / umKrestu / Christen C. Muslim / AmaMaslim / Muslem D. Hindu / umHindu / Hindu E. Jewish / iJuda / Joods F. Other (specify) / ezinye (cacisa) / Ander (spesifiseer) ______________________________________			
11.	How important is your faith or religion to you? (Circle relevant letter(s)) Ibaluleke kanganani inkolo okanye inkonzo kuwe? Hoe belangrik is geloof of godsdiens vir u?	A. Not important at all / Ayibalulekanga kwaphela B. Unimportant / Ayibalulekanga C. Important / Ibalulekile D. Very important / Ibaluleke kakhulu			
12.	In what neighbourhood do you live? Uhlala phi? In watter woonbuurt woon u?				

13.	Would you describe your work status as (Circle relevant letter(s)): Ungawuchaza umsebenzi wakho njenge: Sal u u werkstatus beskryf as:	A. formally employed / ingqesho esesikweni / formeel indiens B. casually employed / usisingxungxi / informele sektor C. self-employed / uyazisebenzela / eie besigheid D. pensioner / umhlaliphantsi / pensionaris E. unemployed / ngongaqeshwanga / werkloos F. Other (specify) / okunye (cacisa) / ander (spesifiseer) ___________________________________
14.	What is your household monthly income? (in rands) (Circle relevant letter(s)) Yimalini ingeniso yakho ngenyanga? (ngerandi) Wat is u maandelikse huishoudelike inkomste?	A. 1 – 500 B. 501 – 1000 C. 1001 – 2000 D. 2001 – 3000 E. Above / ngaphezulu kwe / bo 3000 F. Other (specify) / okunye (cacisa) / ander (spesifiseer) ___________________________________

Section B – The Community (CHBC) Home-based Care Agency
Icandelo B – Iqumrhu lasekuhlaleni lokunakakela
Afdeling B – Die Gemeenskap Tuisgebaseerde Versorgingsagentskap (GTVA)

1	What is the name of the CHBC agency that your VCG works for? Ngubani igama lequmrhu asebenza kulo umvolontiyi wakho asebenzela lona? Wat is die naam van die GTVA wat u VV voor werk?		
2	Where did you first find out about the CHBC agency? (Circle relevant letter(s)) Waqala ukuva phi ngequmrhu lonakekelo lwabantu? Waar het u uitgevind van die GTVA?	A. Provincial Hospital / KwisiBhedlele sePhondo / Provinsiale Hospitaal B. Dora Nginza Hospital / Kwisibhedlele iDora Ngiza / Dora Nginza Hospitaal C. Livingstone Hospital / Kwisibhedlele iLivingstone / Livingstone Hospitaal D. Uitenhage Provincial Hospital / Kwisibhedlele iProvinshiyal saseTinarha / Uitenhage Provinsiale Hospitaal E. Your doctor told you / Uxelelwe ngugqirha wakho / U dokter het u gesê F. Your local clinic / Uve kwiklinikhi ekufuphi / U plaaslike kliniek G. Other (specify) / Ezinye (cacisa) Ander (spesifiseer) _______________________________	
3	When did you first make contact with the CHBC agency? Year(s) and/or Month(s) ago Uqale nini ukunxibelelana nequmrhu lonakekelo? Unyaka okanye inyanga edlulileyo Wanneer het u aanvanklik kontak gemaak met die GTA? Jaar/Jare en/of Maand	Years	Months
4.	How did you make contact with the CHBC agency? Unxibelelane njani nequmrhu lonakekelo? Hoe het u kontak gemaak met die GTA?		
5	Has an agency supervisor/nurse ever visited you in your home? Yes = 1 No = 0 Ingaba owongameleyo /umongikazi wakha wakundwendwela ekhayeni lakho? Ewe = 1 Hayi = 0 Het 'n agentskapstoesighouer/verpleegster u al ooit by u huis besoek? Ja = 1 Nee = 0		
6	If yes, on average how many days per month does the supervisor/nurse visit your home? Day(s) per month <u>or</u> day(s) per year Ukuba uthi ewe, owongameleyo /umongikazi ukuhambela kangaphi ngenyanga ekhayeni lakho? Usuku , iintsuku ngenyanga okanye ngonyaka Indien ja, hoeveel dae per maand gemiddeld het die toesighouer/verpleegster u huis besoek? Dag/dae per maand of dag/dae per jaar	Per month	Per year
7	If no, when was the last time you saw the supervisor/nurse? Year(s) and/or Month(s) ago Ukuba uthi hayi, wagqibela nini ukubona owongameleyo/umongika? Unyaka,iminyaka okanye inyanga edlulileyo Indien nee wanneer was die laaste keer wat u 'n toesighouer/verpleegster gesien het? Jaar/Jare en/of Maand(e) gelede		

Section C – Volunteer Caregiver (VCG)
Icandelo C – umNakekeli oliVolontiya
Afdeling C – Vrywillige Versorger (VV)

1	How many months or years, has your VCG being caring for you? Year(s) and/or Month(s) Zingaphi iinyanga okanye iminyaka umNakekeli wakho ekukhathalele? Hoeveel maande of jare het die VV al vir u gesorg? Jaar/Jare en/of Maand(e)	Years	Months
2	Are you related to your VCG? Yes = 1 No = 0 Uyazalana nomNakekeli wakho? Ewe = 1 Hayi = 0 Is u 'n familielid van u VV? Ja = 1 Nee = 0		
3	If yes, what is his/her relationship to you? (Circle the relevant letter(s)) Ukuba uthi Ewe, uhlobene njani nawe? Indien ja, wat is sy/haar verhouding met jou?	a. Wife / Yinkosikazi / Vrou b. Husband / Ngumyeni / Man c. Mother / Umama / Moeder d. Father / Utata / Vader e. Brother / umnakwenu / Broer f. Sister / udadewenu / Suster	g. Aunt / umalumekazi / Tannie h. Uncle / umalume / Oom i. Cousin / Ukhazi / Niggie/Neef j. Brother-in-law / usiBali / Swaer k. Sister-in-law / usiBalikazi / Skoonsuster l. Other (specify) / abanye (cacisa) / Ander (spesifiseer) ____________________
4.	What basic supplies does your VCG bring you? Ngawaphi amayeza asisiseko owaphathelwa ngumnakekeli wakho? Watter basiese voorrade bring die VV vir u?		
5	Does your VCG provide you with medicine to take away pain? Yes = 1 No = 0 Ingaba umnakekeliwakho uyakunika amayeza okuphelisa iintlungu? Ewe = 1 Hayi = 0 Gee die VV vir u medisyne om u pyn weg te neem? Ja = 1 Nee = 0		
6.	If yes, what types of medicine does your VCG provide you with to help remove the pain? / Ukuba uthi ewe, loluphi uhlobo lwamayeza umnakekeli wakho akunika wona ukuze uncede intlungu? / Indien ja, watter tipe medisyne gee u VV vir u om die pyn tweg te neem?		
7	Are you on medical aid? Yes = 1 No = 0 Ingaba unayo? Ewe = 1 Hayi = 0 Het u 'n mediese fonds? Ja = 1 Nee = 0		
8	Are you happy with the service that your VCG gives you? Yes = 1 No = 0 Uyavuya ngenkonzo yokunakekela oyinikwa yiVCG yakho? Ewe = 1 Hayi = 0 Is u gelukkig met die diens wat u VV vir u gee? Ja = 1 Nee = 0		
9.	Please explain your answer to Question 8. Yicacise le mpendulo yakho ikumbuzo 8. Verduidelik asseblief u antwoord op vraag 8:		
10	Is your family happy with the service that your VCG gives them? Yes = 1 No = 0 Ingaba usapho lwakho luyayivuyela inkonzo oluyinikwa ngumnakakeli wakho? Ewe = 1 Hayi = 0 Is u gesin gelukkig met die diens wat u VV vir hulle gee? Ja = 1 Nee = 0		
11.	Please explain your answer to Question 10. Yicacise impendulo yakho ekumbuzo 10. Verduidelik asseblief u antwoord op vraag 10		
12	How many days per month does your VCG visit you? day(s) per month iVGC yakho ikuhambela iintsuku ezingaphi ngenyanga? Hoeveel dae per maand besoek u VV vir u? Dag/dae per maand		
13	Is it easy to make contact with your VCG? Yes = 1 No = 0 Ingaba kuluka ukunxibelelana nomnakakeli wakho? Ewe = 1 Hayi = 0 Is dit maklik om met u VV in verbinding te tree? Ja = 1 Nee = 0		
14	Do you live within walking distance of your VCG? Yes = 1 No = 0 Ingaba uhlala kufutshane ne umnakakeli wakho? Ewe = 1 Hayi = 0 Woon u binne loopafstand van u VV af? Ja = 1 Nee = 0		
15	Do you have your own house telephone or cell phone? Yes = 1 No = 0 Unayo ifowuni yakho endlwini okanye iselfowuni? Ewe = 1 Hayi = 0 Het u, u eie huistelefoon of selfoon? Ja = 1 Nee = 0		
16.	Please explain how you make contact with your VCG. Nceda ucacise indlela onxibelelana ngayo neVCG yakho. Verduidelik asseblief hoe u kontak maak met u VV:		

17	When was the last time you saw your VCG? day(s) ago or week(s) ago Ugqibele nini ukumbona umnakakeli wakho? Wanneer was die laaste keer wat u kontak gemaak het met u VV? dag/dae of week/weke gelede	
18.	What did your VCG do for you that time? UMnakakeli wakho wakwenzela ntoni ngalo mini? Wat het u VV vir u gedoen?	
19.	What have you learnt from your VCG since she/he started caring for you? Ufunde ntoni kuMnakakeli wakho ukusukela kwixesha lokuqala kwakhe ukukunakakela? Wat het u geleer sedert die VV vir u begin sorg het?	
20.	What are the most important things that your VCG does for you? Zintoni ezona nto zibalulekileyo uMnakakeli wakho akwenzela zona? Wat is die belangrikste dinge wat u VV vir u doen?	

21	Has your VCG helped you with the following? Ingaba uMnakakeli wakho uyakunceda kwezi zinto zilandelayo? Het u VV u met die volgende gehelp? **Has your VCG: Het u VV:**				Yes = 1 No = 0 Ewe = 1 Hayi = 0 Ja = 1 Nee = 0
21.1	Helped you out of bed Ingaba wajkhe wakunceda ukwehlika ebhedini U uit die bed uit gehelp?		21.34	Comforted you when you have been upset? Wakuthuthuzela xa ukhathazekile? U getroos wanneer u ontsteld was?	
21.2	Made your bed? Wakondlulela ibhedi? U bed opgemaak?		21.35	Taken you to the doctor? Wakusa kugqirha? U al dokter toe geneem?	
21.3	Changed your bed sheets? Wakutshintshela amashiti U bed skoon oorgetrek?		21.36	Brought home groceries for you? Wakuphathela igrosari ekhayeni lakho? Kruideniersware vir u huis toe gebring?	
21.4	Positioned you correctly on your bed? Wakulalisa kakuhle ebhedini? U korrek in die bed geposisioneer?		21.37	Helped you pay for your medicine? Wakunceda ukubhatala amayeza? U gehelp om vir u medisyne te betaal?	
21.5	Given you a sponge bath? Wakuhlamba? Vir u 'n sponsbad gegee?		21.38	Done housework for you? Wakucocela indlu yakho? Skoonmaakwerk vir u gedoen?	
21.6	Turned or moved you in and out of bed? Wakuguqula okanye akubeke okanye akohlise ebhedini? U omgedraai of u in of uit die bed gehelp?		21.39	Done your laundry? Wakuhlambela impahla? U wasgoed gedoen?	
21.7	Washed soiled bed linen for you? Wakuhlambela ingubo ezimdaka? Vuilgemaakte bedlinne vir u gewas?		21.40	Helped pay for your food? Wakunceda ukubhatala ukutya kwakho? U gehelp om vir kos te betaal?	
21.8	Taught you physical exercises? Wakufundisa umthambo? U fisiese oefeninge laat doen?		21.41	Cleaned up after you lost bowel or bladder control? Wacoca emva kokuba ushiywe ngumchamo okanye lithafa? / Skoongemaak nadat u beheer oor u blaas of derm verloor het?	
21.9	Prepared meals for you? Wakwenzela ukutya? Maaltye vir u voorberei?		21.42	Cleaned up when you have thrown up? Wacoca emva kokuba ugabhile? Skoongemaak nadat u opgegooi het?	
21.10	Helped you eat a meal? Wakutyisa ukutya kwakho? U gehelp om te eet?		21.43	Change dressings on your sores? Wakutshintsha amabhandeji ezilonda zakho? U verbande op u sere omgeruil?	
21.11	Given you advice about mouth care? Wakunika icebo malunga nokukhathalela umlomo wakho? Vir u raad oor mondhigiëne gegee?		21.44	Helped you in the bathroom? Wakuncedisa xa ukwindlu yangasese? U in die badkamer gehelp?	
21.12	Taught you breathing exercises?		21.45	Helped you with employment advice?	

	Wakufundisa indlela yokuphefumla efanelekileyo? Vir u asemhalingsoefeninge geleer?			Wakucebisa malunga nengqesho? U met werk advies gehelp?	
21.13	Assisted you when you were coughing? Wakuncedisa xa ukhohlela? U gehelp toe u gehoes het?		21.46	Helped you obtain a disability grant? Wakunceda ukuba ufumane isibonelelo semali sikarhulumente? / U gehelp om aansoek te doen vir ‘n ongeskiktheidstoelaag?	
21.14	Assisted you when you were vomiting? Wakuncedisa xa ugaba? U gehelp toe u opgegooi het?		21.47	Helped you to find accommodation Wakunceda ukuba ufumane indawo yokuhlala? U gehelp om akkommodasie te vind?	
21.15	Collected sputum from you? Wathatha isikhohlela sakho? Speeksel van u versamel?		21.48	Helped you with financial advice? Wakunika ingcebiso yemali? U met finansiële advies gehelp?	
21.16	Disposed of your sputum? Wakuchithela izikhohlela zakho? Ontslae geraak van u speeksel?		21.49	Provided you with transportation to the hospital/clinic? Wakunceda ngento yokukhwela ukuya esibhedlele? U met vervoer na die hospital/kliniek gehelp?	
21.17	Taken your temperature? Wathatha ubushushu bakho? U temperatuur geneem?		21.50	Helped draw up a will? Ukwenza umyolelo wakho? U met die opstel van ‘n testament gehelp?	
21.18	Taken your pulse? Weva ukubetha kwentliziyo yakho? U pols geneem?		21.51	Helped you plan for your children’s future? Ukucwangcisela ikamva labantwana bakho? U gehelp met die beplanning van u kinders se toekoms?	
21.19	Put you in the recovery position? Wakubeka ngendlela yokuba ukwazi ukuba ngcono? U in die herstel posisie gesit?		21.52	Made meals/tea for you? Wakuphekela? Maaltye/ tees vir u gemaak?	
21.20	Worn gloves when caring for you? Wanxiba iglavs xa ekunakekela? Handskoene gedra as hy/sy vir u sorg?		21.53	Made meals for other people in your home? Waphekela abanye abantu ohlala nabo? Maaltye vir ander mense in u gesin gemaak?	
21.21	Assisted you in a wheelchair? Wakuncedisa ukuhlala kwisitulo sokuhamba? U in u rolstoel ondersteun?		21.54	Helped tidy your room? Waqoqosha igumbi lakho? U kamer aan die kant gemaak?	
21.22	Given you pressure care? Vir u druksorg gegee?		21.55	Helped tidy the rest of the house? Waqoqosha indlu yonke Die res van die huis aan die kant gemaak?	
21.23	Washed your hair in bed? Wakuhlamba intloko usebhedini? U hare in die bed gewas?		21.56	Done the washing or ironing for you? Wakuhlambela okanye waku ayinela? Die wasgoed of strykwerk gedoen?	
21.24	Given you hand and foot care? Wakuphulula izandla neenyawo? Vir u hand- en voetsorg gegee?		21.57	Done shopping for you? Wakuthengela izinto ozifunayo? U inkopies gaan doen?	
21.25	Assisted you with a bedpan? Wakuncedisa ukuhlala etshembeni? U met ‘n bedpan gehelp?		21.58	Helped you go to the toilet? Ukuya kwindlu yangasese U gehelp met toilet toe gaan?	
21.26	Given you catheter care? Wakuncedisa ukufaka ikhathethi? Vir u katetersorg gegee?		21.59	Helped you with pain relief? Ukuthomalalisa iintlungu? Gehelp met die verlossing van pyn?	
21.27	Tested your urine? Wawuvavanya umchamo wakho? U urine getoets?		21.60	Changed the dressings on your wounds? Wakutshintsha amabhandeji ezilonda?	
21.28	Given you medicines? Wakunika amayeza? Vir u medisynes gegee?		21.61	Massaged you to prevent bedsores? Wakuphulula ukunqanda iingqaqambo zokulala ixesha elide	

				U gemasseer om bedsere te verhoed?	
21.29	Helped you take your medicine? Wakuncedisa ukusela amayeza? U gehelp om u medisyne te neem?		21.62	Decided when you should go to hospital? Wagqiba xa kufuneka uye esibhedlele? Besluit wanneer u hospitaal toe moet gaan?	
21.30	Helped you when you were choking? Wakunceda xa utsarhwayo? U gehelp wanneer u stik?		21.63	Helped you cope with symptoms? Ukumelana neempawu zesifo? Gehelp om simptome te hanteer?	
21.31	Helped you take a bath? Wakunceda ukuba uhlambe? U gehelp om te bad?		21.64	Given you advice about medicines? Ingcebiso malunga namayeza? Raad gegee oor medisynes?	
21.32	Shaved you? Wakucheba iindevu? U al geskeer?		21.65	Given you counselling? Ingcebiso? Vir u beradinggegee?	
21.33	Stopped your bleeding? Wanqanda ukopha kwakho? U bloeding gestop?		21.66	HIV and AIDS education? Ulwazi malunga nentsholongwane kaGawulayo noGawulayo Vir u HIV en VIGS opvoeding gegee?	
			21.67	Other (specify) Ezinye (cacisa) Ander (spesifiseer)	

22.	Do you think that the nurses at the clinic/hospital respect your VCG? Yes = 1 No = 0 Ucinga ukuba abongikazi baseklinikhi /esibhedlele bayamhlonipha umnakakeli wakho? Ewe = 1 Hayi = 0 Dink u dat die verpleegsters by die kliniek/hospital u VV respekteer? Ja = 1 Nee = 0	
23.	Does your VCG give you spiritual support? Yes = 1 No = 0 Ingaba uMnakakeli wakho uyakunika inkxaso ngokwasemphefumlweni? Ewe = 1 Hayi = 0 Gee u VV u geestelike ondersteuning? Ja = 1 Nee = 0	
24.	If yes, how does your VCG give you spiritual support? Ukuba kunjalo, ingaba uMnakakeli wakho ukunika njani inkxaso yomphefumlo? Indien ja, hoe gee u VV u geestelike ondersteuning?	
25.	Has your VCG ever been angry with you? Yes = 1 No = 0 Umnakakeli wakho wakha wanomsindo kuwe? Ewe = 1 Hayi = 0 Was u VV al ooit kwaad vir u? Ja = 1 Nee = 0	
26.	If yes, please describe the incident (s). Ukuba kunjalo,sichaze isiganeko eso. Indien ja, beskryf die incident.	
27.	Are there any issues that you would like to raise concerning your VCG? Ingaba ikhona imiba ofuna ukuyithetha malunga noMnakakeli wakho? Het u enige sake wat u wil ophaal met betrekking tot u VV?	
28.	Do you prefer to have a VCG visit you in your home rather than go to hospital? Yes = 1 No = 0 Ukholwa kukuba uMnakakeli wakho akuhambele ekhaya kunokuba uye esibhedlele? Ewe = 1 Hayi = 0 Verkies u dat u VV u by die huis kom besoek in plaas van om hospitaal toe te gaan? Ja = 1 Nee = 0	
29.	If yes, please explain why. Ukuba uthi ewe, cacisa ukuba utsho ngoba Indien ja, verduidelik waarom:	
30.	Has your VCG helped with answering your questions about health issues? Yes = 1 No = 0 Ingaba uMnakakeli wakho wakhe wakunceda ekuphenduleni imibuzo malunga nemiba yempilo? Ewe = 1 Hayi = 0 Het u VV gehelp met die beantwoording van vra oor gesondheidsake? Ja = 1 Nee = 0	
31.	If yes, please give an example. Ukuba uthi ewe, nika umzekeko Indien ja, gee 'n voorbeeld:	
32.	Are you happy with the way he/she answered it? Yes = 1 No = 0 Wanelisekile yindlela abaphendule ngayo? Ewe = 1 Hayi = 0 Is u gelukkig met die manier waarop hy/sy geantwoord het? Ja = 1 Nee = 0	
33.	If no, do you have any questions you need answering? Ukuba akunjalo, ingaba ikhona imibuzo ekufuneka	

	uyiphendule? Indien nie, het u enige vrae wat beantwoord moet word:	
34.	Have you been able to talk to your VCG about your problems - the things that are worrying you? Yes = 1 No = 0 Ubukhe wanakho ukuthetha noMnakakeli wakho malunga neengxaki zakho- izinto ezikukhathazayo? Ewe = 1 Hayi = 0 Het u al met u VV oor u problem gepraat – die dinge wat u pla? Ja = 1 Nee = 0	
35.	If yes, please give an example. Ukuba kunjalo, nika umzekelo. Indien ja, gee asseblief ‘n voorbeeld.	
36.	Was he/she able to help you resolve this problem? Yes = 1 No = 0 Wakwazi ukukunceda ukusombulula ingxaki yakho? Ewe = 1 Hayi = 0 Was hy/sy in staat om u probleem op te los? Ja = 1 Nee = 0	
37.	If no, do you have any problems you would like to talk to someone about? Yes = 1 No = 0 Ukuba akunjalo, ingaba zikhona iingxaki onqwenela ukuthetha ngazo komnye umntu? Ewe = 1 Hayi = 0 Indien nie, het u enige probleme wat u met iemand wil bespreek? Ja = 1 Nee = 0	
38.	Have you ever had conflict with your family about your illness? Yes = 1 No = 0 Wakha wanengxabano nosapho lwakho malunga nengulo yakho? Ewe = 1 Hayi = 0 Het u al ooit konflik met u familie oor u siekte gehad? Ja = 1 Nee = 0	
39.	Has your VCG helped with resolving (conflict) problems with your friends and family? Yes = 1 No = 0 Ingaba uMnakakeli wakho wakhe wanceda ekusombululeni ingxaki /ingxabano phakathi kwakho nabahlobo kunye nosapho lwakho? Ewe = 1 Hayi = 0 Het u VV gehelp met die oorkoming van die probleem met u vriende en familie? Ja = 1 Nee = 0	
40.	If yes, please give an example. Ukuba kunjalo, nceda unike umzekelo. Indien ja, gee asseblief ‘n voorbeeld	
41.	Do you ever feel lonely or isolated? Yes = 1 No = 0 Ukhe uzive unesithukuthezi okanye uwedwa? Ewe = 1 Hayi = 0 Voel u ooit alleen of geïsoleerd? Ja = 1 Nee = 0	
42.	Has your VCG helped you to feel less lonely or isolated? Yes = 1 No = 0 Ingaba uMnakakeli wakho ukuncedile ukuba ungabinasithukuthezi okanye uwedwa? Ewe = 1 Hayi = 0 Het u VV gehelp om u minder alleen of geïsoleerd te laat voel? Ja = 1 Nee = 0	
43.	If yes, in what way did he/she help? Ukuba kunjalo, wakunceda njani? Indien ja, op hoe ‘n manier het hy/sy gehelp:	
44.	Has your VCG helped you get spiritual (religious) comfort? Yes = 1 No = 0 Ingaba uMnakakeli wakho wakunceda ukuthuthuzela umphefumlo? Ewe = 1 Hayi = 0 Het u VV u gehelp met geestelike vertroosting? Ja = 1 Nee = 0	
45.	If yes, in what way did he/she help? Ukuba akunjalo, wakunceda njani? Indien ja, op hoe ‘n manier het hy/sy gehelp:	
46.	If no, how do you think they could help? Ukuba akunjalo, ucinga bangakunceda njani? Indien nie, hoe het u gedink kan hy/sy help:	
47.	If you have a child, has your VCG helped you care for your child in any way? Yes = 1 No = 0 Ukuba unomntwana, ingaba uMnakakeli wakho ukuncedile ukuba ukhathalele umntwana wakho? Ewe = 1 Hayi = 0 Indien u ‘n kind het, het die VV u enigsins met die kind gehelp? Ja = 1 Nee = 0	
48.	If yes, how has he/she helped? Ukuba kunjalo, wakunceda njani? Indien ja, hoe het hy/sy gehelp?	
49.	Have you had any bad experiences with your VCG? Yes = 1 No = 0 Ingaba unamava angalunganga malunga noMnakakeli wakho? Ewe = 1 Hayi = 0 Het u enige slegte ondervindinge met u VV gehad? Ja = 1 Nee = 0	
50.	If yes, please describe. Ukuba kunjalo, chaza. Indien ja, beskryf asseblief	
51	How do you rate the service provided by your VCG? Uyilinganisa njani inkonzo oyinikwa nguMnakakeli wakho? Hoe evalueer u die diens wat u VV verskaf het?	A. Poor / Lambatha / Swak B. Good / Lungile / Goed C. Very good / Lungile kakhulu / Baie goed D. Excellent / Gqwesile / Uitstekend

Section D – Questions about HIV and AIDS
ICandela D – Imibuzo malunga noGawulayo neNtsholongwane yakhe
Afdeling D – Vrae oor HIV en VIGS

The next few questions are about HIV and AIDS. Le mibuzo ilandelayo imalunga noGawulayo neNtsholongwane yakhe Die volgende paar vrae is oor HIV en VIGS.		
1.	What is AIDS? Yintoni uGawulayo? Wat is VIGS?	
2.	Do you think people can contract the virus that causes AIDS in the following ways: (answer each one) Ucinga ukuba abantu bangosuleleka yintsholongwane ebangela uGawulayo ngezi ndlela zilandelayo (phendula umbuzo ngamnye): Dink u dat mense die virus wat VIGS veroorsaak kan opdoen op die volgende maniere: (antwoord elke een):	
	Yes = 1 No = 0 Unsure = 2 Ewe = 1 Hayi = 0 Akuqinisekanga = 2 Ja = 1 Nee = 0 and Onseker = 2	
A	By sharing knives, forks and plates with some one who has the AIDS virus? Ngokubolekisana ngeemela, iifolokkhwe nepleyit I nomntu onentsholongwane kaGawulayo? Deur messe, vurke en borde met iemand wat die VIGS virus het, te deel?	
B	From a mother who has the virus to her unborn baby? Kumama onentsholongwane kumntwana wakhe ongekazalwa? Van 'n ma wat die virus het aan haar ongebore baba?	
C	From a mosquito bite when the mosquito has bitten someone who has the virus? Ngokulunywa yingcongconi elume umntu onentsholongwane? Van 'n muskietbyt wanneer die muskiet iemand gebyt het wat die virus het?	
D	By hugging someone who has the virus? Ngokugona umntu onentsholongwane? Om iemand wat die virus het 'n drukkie te gee?	
3.	Can the HI-virus be transmitted in the following ways? (answer each one) Intsholongwane kaGawulayo inakho ukusulela ngezi ndlela zilandelayo (phendula umbuzo ngamnye) Kan die HI- virus op die volgende maniere oorgedra word? (antwoord elke een)	
	Yes = 1 No = 0 Unsure = 2 Ewe = 1 Hayi = 0 Akuqinisekanga = 2 Ja = 1 Nee = 0 and Onseker = 2	
A	Through donating blood? Ngokunikezela ngegazi? Deur bloed te skenk?	
B	Through sexual intercourse? Ngokulalana? Deur seksuele omgang?	
C	Through an injection from the doctor? Ngokuhlatywa inaliti ngugqirha? Deur 'n inspuiting van die dokter	
D	If blood enters your body through cuts or sores? Ukuba igazi lingena emzimbeni wakho ngemikrwelo nezilonda? As bloed deur snye of sere by u liggaam inkom	
E	Through sexual intercourse using a condom? Ngokulalana usebenzisa ikhondom? Deur seksuele omgang met die gebruik van 'n kondoom	
4	If both partners are HIV+, do you think they should still use a condom with each other? Ucinga ukuba xa amaqabane omabini eneNtsholongwanane kaGawulayo kufuneka basebenzise ikhondom? As 'n paar HIV+ is, dink u dat hulle nogsteeds 'n kondoom moet gebruik?	
5	As far as you know, do people who have AIDS tell others about their AIDS status? Ngolwazi lwakho ucinga ukuba abantu abanoGawulayo bayabachazela abanye ngemeko yabo? Sover u weet, vertel mense wat VIGS het, vir ander mense hulle VIGS status?	
6.	If yes, please explain. Ukuba kunjalo, nceda u chaze. Indien ja, verduidelik asseblief.	
7.	7. If no, please explain. Ukuba akunjalo, nceda uchaze. Indien nee, verduidelik asseblief.	

Section E – The Client
Icandela E – Umguli
Afdeling E – Die Klient

1.	How many people including you live in your home? (person(s)) Bangaphi abantu ohlala nabo kuquka nawe? (inani labantu) Hoeveel mense woon in u huis? (Persoon/persone)		
2.	Who do you live with? (Circle relevant letter(s)) Uhlala nabani?	A. Alone / Wedwa / Alleen B. Your partner/spouse / Iqabane lakho / U maat/metgesel C. Your partner / spouse and children / Iqabane lakho/umyeni nabantwana / U maat/metgesel en kinders D. Other relatives / Ezinye izizalwane / Ander familielede E. Friends / Izihlobo / Vriende F. Strangers / Abantu ongabaziyo / Vriende G. Other (specify) / Abanye (cacisa) / Ander (spesifiseer) ___________________________	
3.	Are there other adults (other than you) at home during the day? Yes = 1 No = 0 Bakhona abanye abantu abadala ekhayeni ngaphandle kwakho? Ewe = 1 Hayi = 0 Is daar ander volwassenes (behalwe u) gedurende die dag by die huis? Ja = 1 Nee = 0		
4.	How many? (adult(s)) Bangaphi? Hoeveel?		
5.	Are any of these able to look after you when you are sick? Yes = 1 No = 0 Ingaba aba bantu bayakwazi ukukonga xa ugula? Ewe = 1 Hayi = 0 Is enige van hierdie mense instaat om na u te kyk as u siek is? Ja = 1 Nee = 0		
6.	Do any of them look after you when you are sick? Yes = 1 No = 0 Ukhona kubo okongayo xa ugula? Ewe = 1 Hayi = 0 Kyk enige van hulle na u wanneer u siek is? Ja = 1 Nee = 0		
7.	How many people depend on the household / family income? (person(s)) Bangaphi abantu ekhayeni abaxhomekeke kwingeniso yosapho? Hoeveel mense is afhanklik van die huishouding/familie inkomste?		
8.	Do you receive a disability grant? Yes = 1 No = 0 Uyasifumana isibonelelo semali yabakhubazekileyo? Ewe = 1 Hayi = 0 Ontvang u 'n ongeskiktheidstoelaag? Ja = 1 Nee = 0		
9.	Do you attend a clinic or hospital? Yes = 1 No = 0 Uyaya eklinikhi okanye esibhedlele? Ewe = 1 Hayi = 0 Besoek u 'n kliniek of 'n hospitaal? Ja = 1 Nee = 0		
10.	How often do you go? Uya kangaphi? Hoe dikwels gaan u?	Days per week	Days per month
11.	How long do you spend there per visit (in hours)? (hour(s)) Uhlala ixesha elingakanani xa uhambele esibhedlele (iyure) Hoe lank duur u besoek (in ure)		
12.	Does your VCG accompany you? Yes = 1 No = 0 uMnakakeli wakho uyakukhapha? Ewe = 1 Hayi = 0 Begelei u VV vir u? Ja = 1 Nee = 0		
13.	Does your household have a car? Yes = 1 No = 0 Ikhona imoto kwikhaya lakho? Ewe = 1 Hayi = 0 Het u huishouding 'n motor? Ja = 1 Nee = 0		
14.	Does your family take you to the clinic or hospital? Yes = 1 No = 0 Usapho lwakho luyakusa eklinikhi okanye esibhedlele? Ewe = 1 Hayi = 0 Neem u familie u na die kliniek of hospitaal toe? Ja = 1 Nee = 0		
15.	When you go to the clinic or hospital? Do you take (Circle relevant letter(s)): Xa usiya eklinikhi okanye esibhedlele ukhwela: Wanneer u kliniek of hospitaal toe gaan, neem u:	A. Your car / Imoto / U motor B. A taxi / Iteksi / 'n Taxi C. A bus / Ibhasi / 'n Bus D. A friend's car / Imoto yesihlobo / 'n Vriend se motor E. Your VCGs car / Imoto yoMnakakeli wakho / u VV se motor F. Other (specify) / Ezinye (cacisa) / Ander (spesifiseer) _____________________________________	

16.	Do you get any assistance from a social worker on how to care for yourself? Yes = 1 No = 0 Lukhona uncedo olufumana konontlalontle malunga nendlela yokuzinakakela? Ewe = 1 Hayi = 0 Kry u enige ondersteuning van die kliniek/hospitaal? Ja = 1 Nee = 0	
17.	When you are ill do you prefer to be cared for at home or in hospital? Home = 1; Hospital = 2 Xa ugula ukhetha ukuba wongiwe ekhaya okanye esibhedlele? Ikhaya = 1; Isibhedlele = 2 Wanneer u siek is verkies u om by die huis versorg te word of in 'n hospital? Huis = 1; Hospitaal = 2	
18	Under what circumstances (at what times in your illness) would you prefer to be cared for in hospital? Unqwenela ukongiwa esibhedlele xa ukweyiphi imeko yokugula? Onder watter omstandighede (op watter stadium van u siekte) sou u verkies om in 'n hospitaal versorg te word?	
19.	Under what circumstances would you prefer to be cared for at home? Unqwenela ukongiwa ekhaya xa ukweyiphi imeko? Onder watter omstandighede sou u verkies om by u huis versorg te word?	

Section F – Client Observations

Make the following observations:

1.	What kind of home does the client live in? (Circle relevant letter(s))	A. House B. Flat C. Shack D. Hostel E. Shelter F. Hospice G. Other (specify) ______________________________
2.	How many rooms does the dwelling consist of? (Circle relevant letter(s))	A. 1 B. 2 C. 3 D. 4 E. 5 F. More than 5
3.	Comment on the personal hygiene of the PLHA and the family	
4.	Comment on the nutritional state of the PLHA and the family	
5.	Comment on the general condition of the PLHA and the family	
6.	Comment if there are signs of dehydration	
7.	Comment on the progression of the disease	
8.	Comment on the environmental hygiene	
9.	Comment on the state of the toilet, if any	
10.	Comment on the refuse disposal	
11.	Comment on the type, condition of housing and ventilation as well	

	Record time of interview **end**: Hour / Minute (e.g. 9.30, or 14.25)	Hour	Minute

APPENDIX F:

Focus group participants:

Subject information sheets, consent forms and interview schedules

APPENDIX F

Subject Information Sheet for Focus Group Participants

Dear prospective participant,

My name is David Morton. I am a doctoral student in sociology at the Nelson Mandela Metropolitan University (NMMU). As part of my degree, I am conducting a research study on volunteer home-based caregivers.

The main aim of this study is to determine the quality of the care that is provided by volunteer home-based caregivers in the Nelson Mandela Metropolitan Municipality.

I wish to invite you to participate in my study. Please note that your participation is voluntary and that non-participation will have no negative consequences. Should you decide to participate in this study, an interview will be conducted.

Please note that you can withdraw from the study at any time, should you feel that you do not want to continue. If you feel that some of the questions are too personal or if you feel uncomfortable answering them, you have the right to refuse to answer, should you wish to do so. Under no circumstances will any of your responses be shown to anyone other than my two research supervisors and myself. No identifying information will be included in the final report.

To make the interview process easier for me, I would like to make use of a tape/voice recorder, with your permission. However, if you are uncomfortable with this arrangement, I will refrain from using one.

Your participation in this study will help with the monitoring and improvement of the quality of care that is provided by the community home-based care programme. This in turn will benefit the clients of the caregivers.

The outcomes of this research will be sent to all the organisations that took part in the study and from which you can access the study results if you so wish.

Yours faithfully,

David Morton	Professor T.V. Mayekiso
(Researcher) Tel: 076 461 1868	(Research supervisor) Tel: 041-504-2187

CONSENT

I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study.

Participant name printed *Participant signature* *Date*

Name of Person Conducting Informed Consent Discussion/
Witness
(Printed)

Signature of Person Conducting Informed Consent Discussion/ Date
Witness

Investigator signature (if different from above) Date

FOCUS GROUP 1

1. Could you please introduce yourselves?
2. I want you talk as though it's a conversation. You don't need to look at me, just talk amongst each other, and I just want you to share anything that comes to your mind.
3. In your opinion, what do you think are the benefits of home-based care?
4. There has been criticism of the government. How can government change their approach to HBC?
5. With regard to HBC?
6. Ok, lets move onto another topic, slightly different, but you have touched on it already. If you hear the term 'quality' side-by-side with HBC what comes to mind?
7. If the financial situation was perfect how would that affect, we know that it's going to improve the material need, but putting that aside, how else can quality be improved?
8. What is a good salary for a 6-hour day?
9. May I ask, if you had to increase the salary to say R3000 would there be an improvement?
10. What makes a person a good mentor or supervisor? Obviously they play a big role.
11. Still with quality, we spoke about M&E, if you were going to develop indicators for monitoring or evaluating what would come to mind with regard to those indicators to measure.
12. Which brings us back to the supervisors and their mentors, because that is one of the ways, which you can monitor - you have to rely on them to check up on staff to do spot checks.
13. I'm going to finish off now, but I'd like to ask you if you could each of you to give an example of where you have seen high quality HBC, something exceptional, I don't know if you can or maybe your stories are very long, but if anything comes to mind it would be nice if you could share that.

FOCUS GROUP 2

1. This is a very broad and general question. What were your experiences interviewing the caregivers at the different venues. Were there any things which came to you or struck you or which was different that you can recall that took place?
2. Did you experience any difficulties interviewing the carergivers on any of the occasions that you did the interviews?
3. Ok, when you were asking the questions did you get anything back from the caregivers, did they complain or how did they feel about the questions.
4. When you were interviewing them, the venue, the place where you interviewed them was there any experience where it didn’t go as smoothly as you would have liked?
5. Right. And what about the clients? What were your experiences of interviewing the clients in their homes?
6. Were any of the clients unable to actually speak themselves? Or like they weren’t perhaps mentally…?
7. Any other client experiences? Embarrassing, or difficult … bad conditions?
8. Was there any occasion when you felt uncomfortable?
9. Were any of them suspicious. Weary of you, a bit nervous that you are … who are you?
10. They feel better what its about?
11. Sometimes when I looked at the questionnaires there would be a whole page missing, without anything written in. I was wondering if in instances like that, that was sometimes when the client did not want to say anything or was just being stubborn, they wouldn’t share.
12. Or confused? Was there any confusion, at any stage, on their part? Client or caregiver?
13. That’s what I’m also looking at, because I think that sometimes the person you’re interviewing will get a bit annoyed perhaps that they’ve been asked those questions already. Or they might feel frustrated, because they think, “I can’t answer the question, it doesn’t make sense to me,” or “what sort of answer do you want?”
14. That’s good! That’s what I want! Ok, I’m going to ask: What in your opinion is quality care? Have you got any ideas of what you think would be quality care?
15. You can phrase the question in two ways: What is quality care or what is a quality caregiver? What makes the care that they give of a high quality or of a high standard?
16. And how would you measure that?
17. What sort of questions are on the questionnaire that you normally use?

18. If you are a supervisor and you go into a home and you with the client over there and the caregiver is over here and you're watching. How can make sure that that information that you're writing down is reliable that both the client and the caregiver are not being 100% honest?
19. So you look at their relationship?
20. So you think the caregiver should go alone?
21. And how often do you think one should go and see these clients to see if the caregivers are doing their work? If you took one client throughout the year, how often do you think the supervisor should visit?
22. As supervisors, I know its difficult because you don't see them that often, but do you find yourself building a relationship with the client? Do they start to get to know you as well?
23. Have you got any thoughts on those things? Let's start off with your training. Do you think the caregivers that you met and you interviewed, do you think that they've all had adequate training or what's your general feel?
24. Literacy?
25. And when you say *literacy* - literacy in English?
26. You mean English literacy or Xhosa literacy or just general?
27. From what you know about training in general, is it done in such a way that people who are receiving the training can understand it easily, or is it sometimes up there and the people—they're not meeting the people where they should be? What is your view?
28. So then how long, if you were to do training, a person might have Std 1 but it doesn't mean they can't be a good caregiver. How would you reach them? How would you, with training—would you need to have the training over a longer period of time or--?
29. Is the training always in English, or is it sometimes in Xhosa?
30. So there's a need for training in Xhosa. Perhaps not necessarily the literature in Xhosa but the spoken and the visual.
31. Well, as far as you know, with home-based care, how much practical training is there? Is it intensive, or is it very quick?
32. How important is supervision in the care situation? How much of a role does the supervisor play in caregiving? What is the importance of the caregiver? Sorry, supervisor?
33. Do you find that you sometimes have to protect your caregivers from the clients' families?
34. Do you think it will be useful if all supervisors in the metro would form some sort of group, like a support group, but really to kind of standardize things so that their role is clearly outlined, or how do you feel?

35. Have you got anything to say about the willingness to care of the caregivers? Do you think everyone that you encountered was very enthusiastic about caring, or were there any of your caregivers that you interviewed that were perhaps reluctant or not completely committed?
36. One last question about that. How many of the caregivers did you find were frustrated with not having supplies or the equipment to help the clients?
37. Has anyone else experienced supply problems or frustrations or people stopping caregiving because they can’t [get supplies]?
38. Just one last question related to that is just the knowledge levels. Are you comfortable with the knowledge levels of the caregivers that you met? Because you know that we did over 32 [questionnaires] of caregivers and 32 [questionnaires of] clients altogether and in your experience do you think there was good knowledge levels or are you not sure?

APPENDIX G:

Key informant participants:

Subject information sheets, consent forms and sample interview schedule

Subject Information Sheet for Key Informant Participants

Dear prospective participant,

My name is David Morton. I am a doctoral student in sociology at the Nelson Mandela Metropolitan University (NMMU). As part of my degree, I am conducting a research study on volunteer home-based caregivers.

The main aim of this study is to determine the quality of the care that is provided by volunteer home-based caregivers in the Nelson Mandela Metropolitan Municipality.

I wish to invite you to participate in my study. Please note that your participation is voluntary and that non-participation will have no negative consequences. Should you decide to participate in this study, an interview will be conducted.

Please note that you can withdraw from the study at any time, should you feel that you do not want to continue. If you feel that some of the questions are too personal or if you feel uncomfortable answering them, you have the right to refuse to answer, should you wish to do so. Under no circumstances will any of your responses be shown to anyone other than my two research supervisors and myself. No identifying information will be included in the final report.

To make the interview process easier for me, I would like to make use of a tape/voice recorder, with your permission. However, if you are uncomfortable with this arrangement, I will refrain from using one.

Your participation in this study will help with the monitoring and improvement of the quality of care that is provided by the community home-based care programme. This in turn will benefit the clients of the caregivers.

The outcomes of this research will be sent to all the organisations that took part in the study and from which you can access the study results if you so wish.

Yours faithfully,

David Morton	Professor T.V. Mayekiso
(Researcher) Tel: 076 461 1868	(Research supervisor) Tel: 041-504-2187

CONSENT

I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study.

Participant name printed *Participant signature* *Date*

Name of Person Conducting Informed Consent Discussion/
Witness
(Printed)

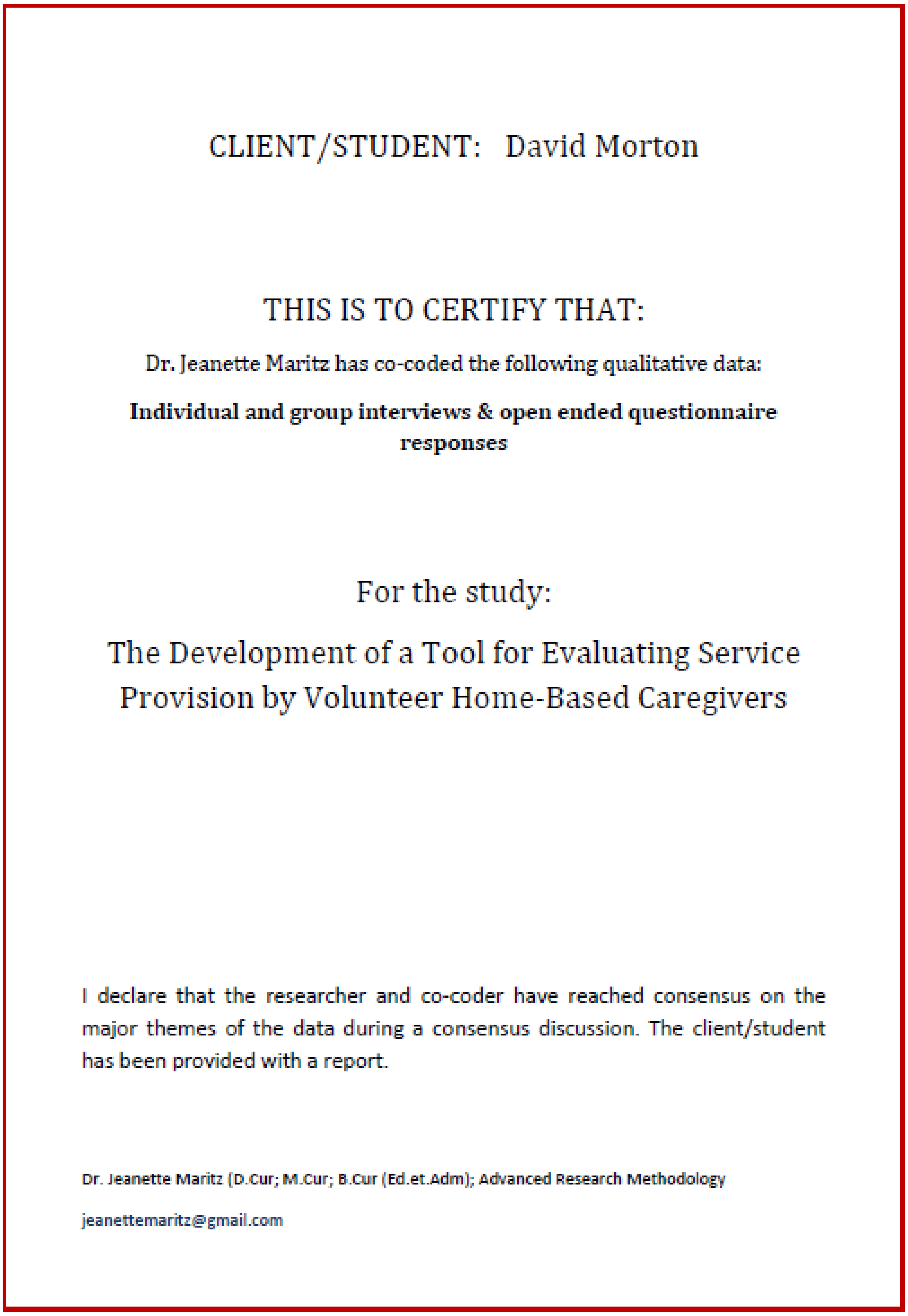
Signature of Person Conducting Informed Consent Discussion/ Witness Date

Investigator signature (if different from above) Date

Sample Interview Schedule

1. You used to work for St. Francis Hospice. What was your role in this organization?
2. What qualifications do you have?
3. What level of counseling training do the volunteers have at St. Francis Hospice?
4. In your opinion, are there any weaknesses in the training programmes for HBC? If yes, what are they?
5. Can they be improved?
6. In your opinion, do you feel that the majority of caregivers (volunteer and paid) in the metro are adequately trained regarding their counseling skills? Please support your answer (That is, have you had feedback?)
7. How can HBC counseling, in the context of the AIDS epidemic, be improved in the metro?
8. Are you referring to the whole Ubuntu concept as well?
9. Where would the starting point be if you were going to start to solve the problem?
10. Are carers given spiritual care training?
11. Is that if you were dealing with one-on-one or the group?
12. Is that what you would instruct your caregivers?
13. In your opinion, what makes a quality caregiver?
14. Do you think that in African culture a female caregiver works best?
15. What is your view on monitoring and evaluation in the context of HBC, especially concerning counseling?
16. So you’re saying that the supervisor’s going to play a big part in drawing out…?
17. Is it about the right questions being asked?
18. Did you ever run an evaluation at St. Francis, did you ever do an evaluation of the caregivers?
19. Can you speak Xhosa?
20. In your view, in the context of HVC, how would you describe QUALITY care?

APPENDIX H:
Independent co-coder’s declaration



CLIENT/STUDENT: David Morton

THIS IS TO CERTIFY THAT:

Dr. Jeanette Maritz has co-coded the following qualitative data:

Individual and group interviews & open ended questionnaire responses

For the study:

The Development of a Tool for Evaluating Service Provision by Volunteer Home-Based Caregivers

I declare that the researcher and co-coder have reached consensus on the major themes of the data during a consensus discussion. The client/student has been provided with a report.

Dr. Jeanette Maritz (D.Cur; M.Cur; B.Cur (Ed.et.Adm); Advanced Research Methodology

jeanettemaritz@gmail.com