Community caregivers: A thematic analysis of the perceived psychological impact that community caregiving has on the caregivers

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Declaration
I declare that, unless specifically indicated to the contrary, this project is the result of my own work. It is submitted in partial fulfillment of the requirement for the degree of: Master of Social Science (Clinical Psychology), Discipline of Psychology, University of KwaZulu-Natal, Pietermaritzburg. It has not been submitted before for any degree or examination in this or any other university.

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Supervisor’s approval of this thesis for submission

As the candidate’s supervisor I have approved this thesis for submission.

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List of Acronyms
AIDS - Acquired Immune Deficiency Syndrome

CBWCY - Community Based Work with Children and Youth

CCGs - Community Caregivers

DCS- Demand-Control-Support

DOH - Department of Health

DOT- Directly Observed Treatment

DSD - Department of Social Development

ERI – Effort-Reward Imbalance

HCBC - Home Community Based Care

HIV - Human Immunodeficiency Virus

JDC- Job-Demand-Control

NGO - Non Governmental Organisation

PHC - Primary Health Care

REPSSI - Regional Psychosocial Support Initiative

SDT- Self-Determination Theory
Abstract
This study focused on the impact of community caregiving work on caregivers. The HIV/AIDS pandemic and other health crises have led to an increased number of orphans and vulnerable children in South Africa. There is hence a growing need for community care workers to assist vulnerable families and children. While it is acknowledged that community caregivers face difficult and ambiguous situations in their work environment, there is a paucity of research on the impact of their work on CCGs.

This study adopted a qualitative approach to explore the work experiences of CCGs and the impact of these experiences on their well-being. Motivational theory and the effort reward model were adopted to provide a framework to examine this question. Twenty eight community caregivers participated in focus group discussions in Pietermaritzburg, KwaMashu, and Osizweni in KwaZulu-Natal.

The findings indicate that community caregivers’ psychological well-being is negatively affected by the challenges they encounter in their work. These leave them feeling exploited, undermined, and vulnerable to harm. The study concludes that poorly functioning referral systems, undermining of caregivers’ roles, a lack of adequate support to deal with work-related stress, and inadequate rewards are some of the challenges that lead to distress among community caregivers. The caregivers felt that increased recognition, adequate rewards, psychological support, and ensuring their safety would have a positive impact on their well-being. While the findings are generalizable, future studies could sample caregivers from various non-governmental organisations and across sectors to strengthen generalizability.
1. Chapter one

1.1 Introduction
A number of epidemics have led to a health crisis in many African countries (Callaghan, Ford & Schneider, 2010). South Africa is one such country which lacks sufficient resources to adequately deal with the health issues confronting it (Bennet, 2004). Concurrent epidemics, especially HIV/AIDS have placed great strain on the health system that is under-staffed and inadequately resourced (Daniels, Clarke & Ringsberg, 2012). In response to the shortage of healthcare professionals, there has been growing emphasis on lay health workers who re-emerged in the mid-1990s (Schneider, Hlophe & van Rensburg, 2008). For the purpose of this study, a lay health worker refers to a person with minimal or no professional training who works in the health care sector. Lay health workers include Community CareGivers (CCGs) and TB DOT (Directly Observed Treatment) supporters. The HIV/AIDS pandemic highlighted the need for such workers (Coovadia, Jewkes, Barron, Sanders & McIntyre, 2009).

This study explored the perceived impact of CCGs’ work on their psychological well-being. It targeted CCGs in KwaZulu-Natal that are participating in the Community Based Work with Children and Youth (CBWCY) certificate programme offered by the University of KwaZulu-Natal (UKZN) in partnership with the Regional Psychosocial Support Initiative (REPSSI) and the KwaZulu-Natal Department of Social Development (DSD).

This chapter provides an introduction to the study. It presents the background of the study, the problem statement and the significance of the study, as well as its objectives. The key concepts and terms used in the study are also defined.

1.2 Background to the study

1.2.1 Community care givers in South Africa: the history
Sub-Saharan African countries suffer resource constraints in providing adequate and appropriate healthcare, while the African continent in general has insufficient health workers (Callaghan, Ford & Schneider, 2010). South Africa is confronted by four concurrent epidemics which significantly impact those who are marginalised: poverty-related illnesses, which include infectious diseases, a high maternal mortality rate and malnutrition; non-communicable diseases;
HIV/AIDS; and violence-related injuries and deaths (Coovadia, Jewkes, Barron, Sanders & McIntyre, 2009).

South Africa’s history had a profound effect on its people’s health and healthcare policies and systems that continues to be felt today. Colonialism and apartheid violently suppressed the indigenous people, seized the land that enabled them to sustain their livelihoods and exploited their labour through the use of unjust laws (Coovadia et al., 2009).

While community health workers programmes declined during the 1980s, the HIV/AIDS pandemic has generated renewed support for such initiatives (Schneider, Hlophe & van Rensburg, 2008). HIV infection rates and AIDS related deaths in South Africa are among the highest in the world (UNAIDS, 2007), with KwaZulu-Natal province home to the highest number of HIV/AIDS infected persons in the country (UNAIDS, 2007).

1.2.2 Community health work in the South African context
The term community health workers was introduced in 2004 as an overall term for all lay workers that work in communities under the health sector and the national Community Health Workers (CHW) policy (Schneider et al., 2008). The revised CHW was formulated to govern the rapidly growing numbers of lay workers in the health sector.

Lay health workers are defined as workers who perform duties related to healthcare provision, with some receiving training, while others receive no training at all. Lay health workers do not have formal education in the form of a professional or paraprofessional certificate or tertiary degree (Daniels, Clarke & Ringsberg, 2012). In response to the shortage of healthcare professionals, South Africa has witnessed rapid growth of a variety of lay workers, including home-based care workers, lay counselors, and DOT supporters (Schneider et al., 2008). The tasks carried out by lay health workers range from palliative care, to counseling, breast feeding support, treatment support, and health promotion, amongst many other tasks (Daniels et al., 2012). Community health workers are not limited to the health department, but have expanded to other sectors in response to community needs and as a job creation strategy (Schneider, Hlophe & van Rensburg, 2008). The DSD has created another category of community care workers that
focus on addressing the needs of vulnerable and orphaned children (Schneider, Hlophe & van Rensburg, 2008).

This study focused on CCGs that provide care in the community in people’s homes. It targeted care workers that address various social welfare needs, as well as those that provide primary care, i.e., those that cater for the immediate needs of the patient, such as cleaning, dressing, and assistance in the bathroom (Peacock & Weston, 2008), while those who provide secondary care work offer support to the primary care-giver (Akintola, 2008). The support provided by CCGs consists of both clinical and non-clinical work. Their work includes connecting community members with appropriate service delivery providers, home care (caring for children, undertaking house chores, and shopping), transportation to health facilities, collecting medication and assisting with financial and legal issues (Akintola, 2008).

1.3 Problem statement and significance of the study
The shortage of healthcare professionals in South Africa has led to an increased need for lay health workers in communities, resulting in rapid growth in the number of such workers. As more households in South Africa are affected by the epidemics bedeviling the country, there is increased need for care and support. More and more households are faced with having to cope with the needs of sick family members, including assistance with daily living, treatment and palliative care. In light of limited access to formal, in-patient programmes, households depend on community caregivers and home-based care programmes for assistance. The epidemics the country faces have resulted in more vulnerable and orphaned children; hence the need for workers at community level to address the needs of these children.

This study sought to understand CCGs’ experiences, focusing on three districts in KwaZulu-Natal. As noted earlier, KwaZulu-Natal is home to the highest number of people living with HIV/AIDS in South Africa (Thabethe, 2011), thus creating the context for CCGs’ experiences in this province. The study aimed to understand the psychological impact on CCGs of working in this context and to determine the support available to caregivers to help them cope.

By providing a better understanding of the psychological impact of being a CCG in the selected districts in KwaZulu-Natal, the study will offer suggestions for effective coping mechanisms and
services that could be made available to caregivers. In designing programmes for community care work, a ‘one-size-fits-all’ approach has proved ineffective because context plays a significant role in caregivers’ experiences (Wringe et al., 2010). Understanding the experiences of the workers in particular contexts will lead to the design of effective programmes with appropriate resources and support systems (Wringe et al., 2010). The study will therefore support the establishment of effective interventions to support caregivers.

The literature on the experiences of CCGs suggests that they face realities that render them vulnerable in their work (Thabethe, 2011). Understanding the psychological impact of these experiences could also assist in shaping CCG programmes that are more effective in catering for caregivers’ needs. When caregivers are well-supported, they are more likely to provide a satisfactory service to the community.

1.4 Definition of terms

Lay health worker

In the context of this study, a lay health worker refers to a person who is either employed or funded by the Department of Health (DOH) and who has minimal or no professional training. The HIV/AIDS pandemic was the main reason for renewed interest in lay health workers because it overburdened the health system to the point where it was unable to meet the health needs of communities (Coovadia et al., 2009). Lay health workers were employed to fill this gap (Callaghan et al., 2010). Lay health worker is an umbrella term that encompasses lay counselors, CCGs and TB DOT supporters.

In South Africa lay health workers perform duties relating to health care provision in communities (Daniels, Clarke & Ringsberg, 2012). They attend to people in their homes as opposed to patients visiting a healthcare institution. The tasks performed by lay health workers include counseling, palliative care, treatment support, breast feeding support, and health promotion (Daniels et al., 2012).
Community caregiver

For the purpose of this study, a CCG is a person who works in the community visiting the homes of community members to attend to their needs. In South Africa, community caregivers are not limited to the healthcare system. The efficiency of CCGs in meeting community needs and the fact that the programme creates jobs has led to CCGs being employed by other departments such as Social Development (Schneider et al., 2008). This study focuses on CCGs funded by the DSD that provide assistance to vulnerable children and families as well as orphaned children (Schneider et al., 2008). This category of CCGs connects community members with appropriate service delivery providers, accompanies clients to health facilities and assists with psychosocial and legal matters (Akintola, 2008).

REPSSI

The Regional Psychosocial Support Initiative (REPSSI) is a non-profit organisation geared towards reducing the distressing effects of HIV/AIDS, poverty, and conflict on children and youth across Southern and East Africa (http://www.repssi.org/about-us/). It aims to empower and protect children and youth by promoting an environment that enables families and community members to nurture them in a manner that supports their psychosocial wellbeing (http://www.repssi.org/about-us/). The REPSSI runs a certificate programme which provides training to CCGS to enable them to work effectively with vulnerable children and youth.

Psychological effects

In the context of this study, psychological effects are the psychological constructs that are affected by the demands of a job (Xanthopoulou et al., 2007). Psychological constructs include insomnia, anxiety, or tension (Rafferty, Friend & Landsbergis, 2001). This study explored how the daily work performed by CCGs affects their psychological well-being.

1.5 Research objectives

The objectives of this research study were to:

- Understand the role of the CCGs on the KwaZulu-Natal DSD’s pay roll.
• Explore CCGs’ experiences and the challenges they face in KwaZulu-Natal province.
• Investigate the perceived psychological impact of community care work environments on CCGs.
• Investigate the coping mechanisms used by CCGs to manage the challenges they face during the course of their work.

1.6 Research questions

- What is the role of the CCGs on the DSD’s payroll?
- What challenges do CCGs encounter in their work?
- What is the perceived impact of the CCGs work experience on their psychological health?
- How do CCGs cope with the challenges they face during the course of their work?

1.7 Overview of chapters

The first chapter provides a general introduction to the study. It sets out the contextual background of the study, highlighting the epidemics that affect the health sector in South Africa which led to renewed enthusiasm for CCGs. The history of CCGs in the South African context and their current role are examined. The chapter also presents the problem statement and significance of the study, as well as its objectives. Finally, the key concepts and terms used in the study are defined.

Chapter two reviews the literature relevant to this study. It focuses on the role played by CCGs and the training that they receive in order to fulfil these roles. Caregivers’ experiences in their work environment are explored, focusing on the challenges they encounter. This is followed by a discussion on the impact of these work experiences on CCGs’ psychological well-being. The coping mechanisms employed by CCGs and the support received from their employers are also examined.

The second part of this chapter presents the theoretical framework that underpinned the study. The Self-Determination Theory was used to consider the psychological effects of the work environment on an individual. The demand-control, demand-control-support, and effort-reward
imbalance models formulated by Keresek and Siegriest are also discussed as their core assumptions were used to explore the relationship between work and health.

Chapter three presents the research methodology employed for this study. It discusses the study design, study area, sample, data collection procedures, data analysis, validity, reliability, generalizability, and ethical considerations.

Chapter four presents the findings of this study according to the themes that emanated from the data and an analysis of the themes.

Chapter five discusses the study’s results on the role of CCGs, their training, the challenges they encounter in their work, and the impact of these challenges. It concludes by discussing the coping strategies adopted by CCGs and the support available to them.

Chapter six summarises the study. It begins by presenting the background and motivation for the study. It then presents the research questions which the study sought to answer. A summary of the findings follows as well as a discussion of the study’s contribution to knowledge. Finally, the chapter discusses the implications of the findings, recommendations, and the study’s limitations.

1.8 Conclusion
Community caregivers play a vital role in South African communities as they ease the load on government systems (Callaghan et al., 2010). While the work that CCGs carry out in their communities exposes them to numerous vulnerabilities (Thabethe, 2011), there is a paucity of research on the impact of community caregiving work on CCGs.

This study employed a qualitative approach to gain an in-depth understanding of CCGs’ experiences of their work and the impact of these experiences on their well-being. Its findings could assist in improving support structures for CCGs in order to assist them to better cope with their work.
Chapter two

2 Literature review

2.1 Introduction
Epidemics such as HIV/AIDS have led to task shifting in South Africa in an effort to meet the health needs of citizens (Fatti, Meinjies, Shea, Eley & Grimwood, 2012). The shortage of health professionals has fueled enthusiasm for the use of lay health workers. Community caregivers fall under the umbrella of community care workers and are the government’s community level approach to dealing with the country’s health crises.

This chapter presents a review of the literature on CCGs’ experiences and how these experiences impact on caregivers. The self-determination framework is used to understand the impact of the work environment on the psychological well-being of CCGs. The chapter begins by examining the origins of CCGs. It goes on to discuss the history of CCGs in South Africa and the South African government's views on CCGs. A profile of a CCG is presented in order to understand the type of person who chooses to be a CCG. The role of CCGs in South Africa, how it has evolved over the decades, and how this role differs from other contexts is examined. The training received by caregivers and the tasks that they perform in communities are discussed as well as the challenges encountered, the impact of these challenges on CCGs’ psychological well-being, and the coping strategies they adopt.

2.2 Origins of community caregivers
The deployment of lay health auxiliaries or lay health workers to assist community members dates back to the 1950s (Friedman, 2005). It is recognised that such workers are effective and that they play a vital role in improving the primary health services delivered in communities (Friedman, 2005). For example, they offer holistic health care to chronically ill elderly people (Christianson, Warrick, Netting, Williams, Read & Murphy, 1991) that hospital staff cannot provide due to staff shortages. Lay health workers thus see to the rehabilitation, medical, and social welfare needs of acutely ill individuals (Christianson et al., 1991).
The lengthy and extensive care required by patients suffering from chronic conditions would drain health institutions’ resources, especially in light of the HIV/AIDS pandemic (Friedman, 2005). Programmes that encourage caring for people living with HIV/AIDS at home instead of health institutions were developed in North America and Europe when it became apparent that the epidemic was exhausting hospital resources and families were struggling to cope on their own (Uys, 2002). Patient care in the community not only offers comprehensive services, but is also cost effective (Uys, 2002). In South Africa, these programmes were first developed in the 1980s due to the HIV/AIDS epidemic; however, they struggled during the early 1990s when the national DOH was reluctant to fund them (Friedman, 2005). This led to hospitals and hospices being overburdened and in the late 1990s, community workers started receiving training at these health institutions.

2.2.1 The history of community caregivers in South Africa

HIV/AIDS is one of the most rapidly growing epidemics in the world, and South Africa has over 5.5 million people living with the virus (Mabude, Beksinska, Ramkissoon, Wood & Folsom, 2008). In 2007, it was estimated that 30.2% of women attending antenatal clinics were HIV positive (Mabude et al., 2008). The pandemic has overstretched public healthcare services (Mabude et al., 2008) and families have had to take it upon themselves to care for people living with HIV (Mabude et al., 2008). While treatment has become progressively more available, the burden of physical care that is required by people living with HIV and AIDS still falls largely on family members.

The DOH often relies on a person’s natural support system to take care of him/her (Conklin, 1980). This includes community members, family, priests, and traditional healers, especially for those living in rural areas (Conklin, 1980). However, the former close knit relationship between community members has been eroded over the years and nowadays many people rely on their family members for assistance with any matter, including health care.

In African countries, most of the care required by the sick need is provided by family members (Rajaraman, Earles & Heymann, 2008). AIDS related illnesses result in patients being unable to take care of themselves and relying on others, usually family members, to do so. In low income
homes, it is not always possible for a family member to provide full time care, because they have to work in order to fulfil their basic needs (Rajaraman et al., 2008). This creates a situation where the infected person is neglected and his/her health is further weakened. The extended family safety net in South Africa is thus strained to its limits (Rajaraman et al., 2008). Family members are heavily burdened with the responsibility of caring for infected family members and some people have nobody to care for them. AIDS-related illnesses and deaths have aggravated the situation (Rajaraman et al., 2008).

The HIV/AIDS pandemic was a major reason for renewed enthusiasm for community health worker programmes that fell into decline in the 1980s (Schneider, Hlophe & van Rensburg, 2008). In 2002, which was declared the Year of the Volunteer by the South African government, campaigns were launched to rally community volunteers not only in the health sector, but across all sectors (Schneider, Hlophe & van Rensburg, 2008). Initiatives such as auxiliary workers established by the DOH spread to other departments such as Social Development that now has auxiliary workers that promote social welfare (Friedman, 2005). Community worker categories include “Community Development Workers, Community Development Practitioners, Mid-level Worker, Community Caregivers, Community Health Workers, Child and Youth Care Workers, Youth Worker, Probation Officers/Community Service Officers and Early Childhood Development Practitioners” (Schneider et al., 2008, p. 181). Schneider et al. (2008) note that all these workers come together under the banner of the Expanded Public Works Programme (EPWP), a government poverty alleviation strategy. The EPWP is associated with the Department of Labour’s National Skills Development Strategy which provides community-based training for community workers (Schneider et al., 2008). The term community health workers was introduced in 2004 as an umbrella term for lay workers that work in communities under the health sector and the national Community Health Workers (CHW) policy (Schneider et al., 2008). The revised CHW policy was developed in 2004 to govern the rapidly growing numbers of lay workers in government sectors.

2.2.2 The South African government's views on community caregivers
As noted earlier, national government departments were initially skeptical about funding community caregivers (Friedman, 2005), who at the time were mainly health workers who
attended to health needs at community level. This attitude changed due to recognition that the community level approach alleviates the strain on the health system. The positive impact of community caregiving work in meeting community needs led to the Minister of Health and the DOH encouraging other departments to establish programmes that employ trained lay people to deliver services in disadvantaged communities (Friedman, 2005). National government now provides funding to provincial governments to fund various NGOs that run CCG programmes (Daniels et al., 2012). External donors also fund some of these NGOs (Daniels et al., 2012).

The implementation of policies to regulate CHWs in South Africa commenced in 2004 (Daniels et al., 2012). Broadly, the policies address the rationale for CHWs, their role in the communities where they work, the education and training of CHWs, supervision and mentoring and the logistics of each programme (Friedman, 2005). However, while policies have been put in place, there still are blurred boundaries with regard to the roles and expectations of various community workers (Schneider & Lehmann, 2010). Different departments such as the DOH and DSD fund community workers who provide services in line with their departmental obligations to communities, while some work full time as community caregivers but earn no stipend. Expectations of community workers may not be fulfilled. Context plays an important role in determining expectations and boundaries.

2.3 The community care giver in context
Context is an important factor in determining what being a lay health worker entails. The role of a lay health worker may vary over time and from context to context. It has been noted that HIV and AIDS-related illnesses have been a major reason for rekindled enthusiasm for lay health workers. The table below from Schneider and Lehmann (2010) shows the origins and values of different types of lay health workers.
The above lay health workers constitute what are now termed CCGs in South Africa. According to the CCG policy framework, CCGs are part of the health and social development teams whose roles are contextualised within social development, Home Community Based Care (HCBC) and Primary Health Care (PHC) services (www.cindi.org.za).

### 2.4 Profile of a CCG
Community caregivers are mostly women (Uys, 2002), which is no surprise as most of the tasks that were performed by the first cohorts of CCGs were those that centered around household work and caring activities, tasks that society perceives as performed by women (Akintola, 2006). While some men have joined the community caregiving field of work, they remain in the minority. Furthermore, CCGs are often unemployed, have no professional training, and come from unfavourable socio-economic backgrounds (Akintola, 2006).
Becoming a CCG requires one to give of one’s time, effort, and sometimes financial resources in order to help someone else (Akintola, 2011). A sense of altruism is required, as not all CCGs are paid and some caregivers volunteer their time and effort (Akintola, 2011). The main motivation for becoming a CCG is that it could lead to formal and improved employment opportunities (Naidu & Sliep, 2012). Other motivations included self-development, being recognised in the community, genuine concern for others, and wanting to avoid idleness (Akintola, 2011).

The standard profile of a CCG is thus a person from a deprived socio-economic background, who is compassionate and hardworking, and has a desire to assist other people. Community caregiving is viewed by this person as an opportunity to improve their financial circumstances and develop skills which could lead to a more formal career, and as a chance to make a difference in other people’s lives.

2.5 The role of a CCG: are CCGs adequately equipped and prepared for their work?

Hermann, van Damme, Pariyo, Schouten, Assefa, Cirera and Massavon (2009) state that in order for any community caregiving programme to be successful, eight conditions must be fulfilled. These are selection and motivation; initial training; simple guidelines and standardised protocols; supervision, support and a relationship with formal health services; adequate remuneration/career structure; political support and a regulatory framework; alignment with broader health system strengthening; and flexibility and dynamism. This section focuses on the second of the eight conditions, initial training, as it has been shown to be vital in the success of a community caregiving programme. The length and content of the training provided to CCGs is of utmost importance (Hermann et al., 2009). Adequate training ensures that quality and effective services are provided to the community, which also affects the success of the programme. According to Hermann et al. (2009), training should focus on the practical aspects of learning, and should not be solely about transferring disease-specific knowledge. In addition to practical skills, caregivers should be equipped with communication and counseling skills (Hermann et al., 2009). Sufficient training also benefits caregivers because it helps them to feel competent and confident in the work they do, and enables them to respond appropriately to challenges at work.
According to Gill, Greenberg and Moon (2007), employing certified nurses to conduct home visits would benefit the community because they are properly trained and are trusted due to their association with the medical profession. While this may be an ideal solution, it is not viable due to financial constraints and the shortage of nurses (Gill et al., 2007). This motivated the DOH to employ lay health workers such as CCGs to cater for people’s needs in their homes. However, CCGs do not have formal training (for professional development) and some have no training at all. Furthermore, CCGs have diverse educational backgrounds, and a range of skills and experiences, which could affect them and the service they deliver (Gill et al., 2007).

According to Demmer (2007), community caregivers are mainly women from local communities who are trained for three months in home care skills and palliative care. They are provided with brief training and are supervised by nurses (Demmer, 2007). It is thus evident that CCGs receive little or no training for the enormous amount of work that they do.

Zachariah, Teck, Buhendwa, Fritzeland, Labana, Chinji, Humblet and Harries (2006) conducted research on antiretroviral treatment in a rural district in Malawi. They examined the training provided to caregivers to enhance their efficacy of caring for HIV infected community members. The volunteers that worked in Thyolo, an under-resourced rural district in Malawi, covered a curriculum which covered various issues relating to HIV, including adherence counseling for antiretroviral treatment, TB prevention, and home-based care activities (Zachariah et al., 2006). The curriculum aimed to formally prepare the volunteers theoretically and ran for two weeks (Zachariah et al., 2006). The volunteers also received on the job training supervised by a community nurse (Zachariah et al., 2006). They were trained to detect risk situations which require the attention of a nurse or health facility (Zachariah et al., 2006).

The volunteers involved in this community care programme were organised into groups depending on where they were geographically located (Zachariah et al., 2006). They were assigned to areas close to their homes and each took care of eight to 12 patients. The volunteers were supervised and supported by a community nurse, each of whom supervised roughly 50 volunteers (Zachariah et al., 2006). Volunteers were supplied with a home-based care kit with
basic drugs and the material required to attend to first line care for conditions like diarrhea, fever, common skin conditions and oral thrush (Zachariah et al., 2006).

2.6 Experiences of CCGs
Community caregivers touch on a variety of fields through the services they provide to community members. Skills from various fields like nursing, gerontology, psychology, and rehabilitation medicine, amongst others are used to care for community members (Mavundla, Toth & Mphelane, 2009).

Mkandawire and Muula’s (2005) study in Malawi sought to determine what motivated CCGs in a peri-urban area of Blantyre. These CCGs served vulnerable groups including chronically ill people, those infected with HIV/AIDS, the elderly, young people and orphans (Mkandawire & Muula, 2005).

The services provided by CCGs included doing household chores (cleaning the house, sweeping the yard, cooking and any other chore required), visiting the sick, and bathing patients. Some also reported that they paid school fees for orphaned children who were in high school (Mkandawire & Muula, 2005). The caregivers also brought food for the families, accompanied the sick to hospital if they had no one else to accompany them, accompanied those who wanted to test for HIV to testing centres, and provided HIV counseling to those who needed it (Mkandawire & Muula, 2005). In some instances the caregivers offered psycho-spiritual support, mainly through prayer (Mkandawire & Muula, 2005).

While the tasks performed by CCGs vary from programme to programme, according to Lund (2010), they generally include training household members in health-related tasks, offering emotional and spiritual counseling, administering medication, palliative care, and performing chores such as cooking and cleaning. In addition to these services, Wringe et al. (2010) cite educating household members, assistance with forming peer support groups for People Living with HIV (PLHIV) and help with income-generating activities. In 2013/4, the South African Minister of Social Development launched a project called “isibindi”, which means courage. This project aimed to assist orphaned and vulnerable children. Community caregivers were employed and tasked with identifying households with vulnerable children who are in need of assistance.
The children are assisted with registering for social grants, and housing, and with daily tasks such as preparing meals, and completing homework. The caregiver’s role extends to providing emotional support, comfort, and reassurance when the child needs it.

Rudolph, Ogunbodede and Mistry (2007) state that CCGs have enormous potential to address the challenges caused by epidemics in South Africa through the role they play in communities. Their roles include counseling the physically, mentally and spiritually ill. They also visit homes on a regular basis to provide support and love to those who need it and uphold the confidentiality of what is shared with them and what they may learn about a person (Rudolph et al., 2007).

2.7 Mental health consequences of being a CCG

There have been few studies on CCGs in South Africa and the research that has been conducted provides little information on how CCGs themselves cope psychologically (Akintola, 2008). While it is clear that CCGs play a major role in assisting the DOH to cope with the epidemics in the country, little is known about caregivers’ well-being (Akintola, 2008). Akintola’s study on the challenges faced by caregivers and how they cope with these challenges in an exception.

Stress is one of the major impacts of community caregiving work on caregivers (Akintola, 2008). Various situations can give rise to stress and difficulty in coping.

The environments where CCGs carry out their tasks are often distressing. Caregivers sometimes have to deal with hostile community and family members who see them as hastening the death of their loved ones, increasing the likelihood of burnout among caregivers (Demmer, 2007). Community members are not always welcoming and supportive of CCGs, possibly because CCGs were previously tasked with ensuring a peaceful death for persons to whom the health system could offer no further hope (Claxton-Oldfield & Claxton-Oldfield, 2007).

Furthermore, poor communities are most in need of the services of CCGs. This creates a situation where the poor tend to the poor (Thabethe, 2011). Some of the caregivers that participated in Thabethe’s (2011) study reported that they sometimes go to work hungry. They have their own economic burdens, yet are required to assist in environments that are very much
like their own. Many caregivers experience emotional and socio-economic stress (Daniels et al., 2012). Akintola (2008) reports that many CCGs identify poverty as an issue that needs to be addressed as it causes stress for the patient and themselves as caregivers. The closeness or familiarity between the caregiver and patient sometimes means that the caregiver feels obliged to assist the patient from their own pocket. While some CCGs have assisted poverty stricken families to access grants, this is not the case for all families, and unsuccessful attempts cause stress (Akintola, 2008).

Furthermore, CCGs endure ambiguous and difficult working conditions (Daniels et al., 2012). One of the main stressors is uncertainty about whether they should be regarded as volunteers or fulltime members of the health system (Daniels et al., 2012). This creates suspicion among community members who are not sure who CCGs are answerable to (Daniels et al., 2012). Such uncertainty has also led to poorly understood and regulated policies for CCGs (Daniels et al., 2012) which makes these workers vulnerable to exploitation.

Family members are sometimes in denial about the severity of the illness of their family member whom the caregiver has come to assist (Akintola, 2008). This is usually coupled with fear of stigmatisation. Family members chase caregivers away because they are seen as verifying that there is a terminally ill person in their home (Akintola, 2008). Discrimination against patients by family members is a constant stressor for volunteers (Akintola, 2008). The family members of HIV infected patients commonly discriminate against sick relatives because they lack knowledge of how the virus is spread. This becomes a stressor to caregivers when the patients informs them how family members ill treat them.

The physical condition of the patient that the caregiver is caring for is another stressor (Akintola, 2008). Some caregivers find it traumatic to deal with bedridden patients and ask their supervisors to assign them to less sick patients (Akintola, 2008). One of the caregivers in the study conducted by Akintola (2008) reported crying profusely while assisting a bedridden patient. The physical condition of the patient worried her and greatly affected her emotionally.

Further problems confronted by CCGs include the lack of integration and conflict with health professionals (Schneider et al., 2008). Community caregivers are supervised by professional nurses and the working relationship is not always good. Caregivers are often regarded as ‘just
another pair of hands’ (Schneider et al., 2008). Related to the lack of integration are the problems of poor supervision, unsupportive environments and unrealistic expectations of CCGs on the part of supervisors (Schneider et al., 2008).

The death of a patient is emotionally draining and can lead to some caregivers wanting to quit (Akintola, 2008). The caregivers that participated in Akintola’s (2008) study said that they were not sufficiently trained and equipped for some situations and that by the time emergency help arrived, they would have already lost the patient, negatively affecting them emotionally.

2.8 Managing the demands imposed by working as a CCG
In terms of the support available to CCGs, there first level is the programme coordinator, who could be the professional nurse in charge of supervising caregivers (Lund, 2010). Her/his task is to ensure that caregivers perform their duties and to listen to CCGs’ concerns and experiences. The nurse takes on the role of a highly-skilled worker who transfers her/his skills to less-skilled workers, the CCGs, in order to enable them to cope in their placements. Having the skills required to deal with their assigned tasks enhances CCGs’ self-confidence and coping skills. The nurse in charge of the caregivers also provides support to caregivers, be it in relation to the challenges they face, work matters or emotional issues.

Many of the participants in Claxton-Oldfield and Claxton-Oldfield’s (2007) study reported that taking time off from community care was a useful coping mechanism as it helped them to regroup. Caregivers confront numerous, difficult challenges in their work, and continuous exposure to the environments in which they work may be draining and emotionally exhausting. Taking time off offers a chance to refocus and recuperate.

Other coping mechanisms cited by the study participants were listening to music, reading a book, and talking to colleagues (Claxton-Oldfield & Claxton-Oldfield, 2007). However, these strategies may not be relevant in the contexts where the current study was conducted, firstly because caregivers have varying educational backgrounds and reading might not be an option for some, and secondly, because caregivers that are overloaded with patients and have to tend to their own homes might not have time to unwind.
Talking to colleagues was identified as a major coping mechanism, because it allowed caregivers to discuss their challenges with people in similar working environments that may experience similar challenges. Sharing with others enables one to identify strategies to tackle certain challenges and acts as a support group.

In Thabethe’s (2011) study, caregivers in KwaZulu-Natal were asked how they cope with the stress that arises as a result of community caregiving. Some reported that they do nothing and that the stress goes away over time (Thabethe, 2011). Hoping that the stress will go away on its own could be an indication of a lack of coping skills or not having the resources to reduce stress. Other caregivers reported that their work stress significantly impacted their private relationships, and that they dealt with it by going to church and praying about what was stressing them (Thabethe, 2011). Prayer is therapeutic and reading the bible would be a motivating factor. A caregiver reported that going to church renewed her faith, reminded her of the importance of serving others and gave her the strength to carry on (Thabethe, 2011).

Lindsey, Hirschfeld, Tlou and Ncube’s (2003) study on the experiences of home-based caregivers found that taking care of the health needs of the sick caused them to feel exploited, depressed and psychologically distressed. The literature notes that caregivers confront many challenges caregiver and such challenges may vary by context which is why it is important to understand experiences in a specific context in order to address these issues appropriately.

As noted earlier, the HIV/AIDS pandemic led to renewed enthusiasm for the use of CCGs. This pandemic has impacted differently on different provinces in South Africa, with KwaZulu-Natal worst-affected (Manning, 2003). This is believed to be the result of a number of factors, “including poverty, migration, social disruption and violence, a high-quality road network, and proximity to the busiest port in southern Africa” (Manning, 2003, p. 6). It is therefore necessary to understand the context-specific challenges confronting CCGs in this province.
2.9 Theoretical framework

2.9.1 The Self-Determination Theory
Motivation is an important construct which has led to much research on this issue (Chambel, Castanheiru, Oliver-Cruz & Lopes, 2015). The consequences of motivation include action and direction, meaning that motivated individuals are likely to have a strategy and route that they follow (Deci & Ryan, 2000). Motivated individuals are not passive but take action and plan ahead. The core assumption of the Self-Determination Theory (SDT) is that the tasks that individuals tackle or become involved in are driven by a variety of reasons that, in turn, influence their behaviour and well-being (Chambel et al., 2015).

The SDT proposes that each person has an intrinsic tendency to develop (Chemolli & Gagne, 2014) by integrating their experience into the self (Chemolli & Gagne, 2014). This natural tendency incorporates internalisation of behaviours which were once alien to the self but have now become valuable. Although this tendency is said to be natural, factors such as personal history, context, and the characteristics of the activities have an impact on internalisation (Chemolli & Gagne, 2014).

The quality of motivation is regulated by the type of internalisation that took place. Internalisation can be intrinsic, where interest is developed in a certain activity because it is enjoyable, or it can be of an identified nature where the person values the outcome of the activity. Finally, internalisation can be of an introjected nature, where behaviour is internalised in its original external form as it forms part of the self (Chemolli & Gagne, 2014).

Employees engage with their work tasks or other activities in different ways, with the approach determined by the nature of motivation. Intrinsically motivated people engage optimally in an activity with desire (van Beek, Taris & Schaufeli, 2011), whereas extrinsically motivated individuals perform a task because of its instrumental value (van Beek et al., 2011).

The continuum of motivation ranges from no-self determined to self-determined behaviour. Behaviour that is motivated by external eventualities such as material gain or loss, punishment, or social rewards is externally regulated behaviour (van Beek et al., 2011). In the workplace, employees who are extrinsically motivated may perform their work mainly because it provides
an income or it keeps them from being laid off (van Beek et al., 2011). Their behaviour is regulated by forces in the environment and is therefore non-self-determined.

People may rigidly adopt standards of self-worth that are external to the self because they lead to social approval even though the individual may not fully identify with such standards (van Beek et al., 2011). This is an example of introjected regulation, where activities are performed to enhance esteem and self-worth (van Beek et al., 20110). In the workplace, people who are introjectedly motivated perform their work tasks because this leads to positive feelings and makes them feel worthy.

Identified motivation occurs when people identify with the reason for a particular activity and it forms part of self (van Beek et al., 2011). Employees whose motivation is identified in nature may perform tasks because they are important and form a vital part of the path they want their careers to take (van Beek et al., 2011).

Integrated motivation takes place when particular behaviour is viewed as consistent with other values and needs that the individual has integrated as part of them (van Beek et al., 2011). Integratedly motivated employees perform their work tasks because this is consistent with their core values.

According to Deci and Ryan (2008), in order for one to function effectively and to be psychologically healthy, a set of basic, universal psychological needs have to be satisfied. The SDT holds that the three basic needs which are universal and enhance one’s well-being are competence, relatedness, and autonomy (Deci & Ryan, 2008). The need for autonomy refers to a desire to own one’s behaviour and to have a sense of choice in one’s actions (Albrecht, 2015). The need for relatedness relates to an innate motivation to feel understood, connected, and accepted by other people (Albrecht, 2015). The need for competence describes a person’s intrinsic desire to feel effective when they interact with the environment within which they exist (Albrecht, 2015). When these psychological needs are satisfied, people are more energetic and positive in the manner in which they tackle tasks which in turn enhances their well-being.

The way in which people initiate and regulate their behaviour as well as the extent of their self-determination in various situations is determined by their general motivational orientation, which is termed causality orientation (Deci & Ryan, 2008). Deci and Ryan (2008) identify three
orientations, autonomous, controlled, and impersonal. When the three psychological needs are continuously fulfilled, this results in a strong autonomous orientation. A work environment which encourages an autonomous orientation promotes psychological health. When the autonomous need is thwarted, but the competence and relatedness needs are fulfilled, controlled orientation is developed (Deci & Ryan, 2008). Finally, impersonal orientation occurs when all three needs are hindered.

According to the SDT, every person has a certain level of each the above-mentioned orientations. Predictions regarding psychological health and behavioural consequences can be made using one or more of these orientations. According to this theory, constructive behavioural outcomes and good psychological health are positively related to the autonomy orientation (Deci & Ryan, 2008). Rigid functioning and diminished well-being are associated with the controlled orientation, while impersonal orientation is associated with the symptoms of being unwell such as lacking vitality and feelings of unworthiness as well as poor functioning (Deci & Ryan, 2008).

The theory also posits that long term life goals have an impact on a person’s health and well-being. Life goals are separated into two categories, namely, intrinsic and extrinsic aspirations. Life goals such as generativity, personal enhancement and affiliation fall under intrinsic aspirations (Deci & Ryan, 2008) while those such as monetary gain, appeal, and fame are associated with extrinsic aspirations. Improved health and performance occurs when there is emphasis on intrinsic rather than extrinsic goals.

The self-motivation theory focuses on the social and environmental factors that either enhance or diminish healthy psychological adjustment and self-motivation (Bartholomew, Ntoumanis, Ryan, Bosch & Thogersen-Ntoumani, 2011). The human psyche is endowed with partialities which assist with growth and integration (Bartholomew et al., 2011). According to the self-motivation theory, the social environment within which a person engages can either facilitate or thwart growth and integration (Bartholomew et al., 2011). A person’s behaviour and experiences are influenced by their social environment. Effective functioning and healthy development is thus promoted by a good environment ((Bartholomew et al., 2011).

In the context of the current study, when autonomy, competence, and relatedness at work are satisfied, this will lead to more meaningful experiences and a positive attitude towards work. The
SDT encompasses motivation which is intrinsic and comprises of complete self-determination as well as motivation which is external to the self and lacks self-determination. Self-determination motivation lies on one end of the spectrum, with non-self-determination motivation at the opposite extreme, with a continuum of various types of extrinsic motivations, namely externalised, introjected, identified, and integrated motivations, in between. Extrinsic motivations lie closer to non-self-determination and integrated motivations lie closer to self-determined motivation on the continuum. According to this theory, for self-determination to occur there needs to be an environment that nurtures it. An environment that leads to the satisfaction of basic psychological needs fosters self-determination and hence better work engagement which in turn has a positive effect on well-being. The CCGs’ accounts of their experiences in the communities within which they work revealed information on their environment and its effect on their motivation and hence work engagement and psychological well-being.

2.9.2 The Job-Demand-Control (JDC) model
The JDC model also assists in understanding the relationship between the workplace and individual well-being. A number of theoretical models have been used to explore the relationship between the nature of the work a person does and their well-being, particularly psychological well-being. Models such as Karasek’s Demand-Control model, the Effort-Reward-Imbalance model by Siegrist, and Kerasek and Theorell’s Demand-Control-Support model are used to explore the relationship between work and health. All these models developed from the JDC model formulated by Karasek in 1979. The model has since been developed to address identified flaws.

Jobs that demand a lot of effort from an individual may lead to exhaustion, energy depletion and a variety of other health problems (Xanthopoulou, Bakker, Demerouti & Schoufet, 2007), including psychological constructs which may also be negatively affected by exposure to strenuous work (Xanthopoulou et al., 2007). Such constructs include tension, anxiety, and insomnia, to name but a few (Rafferty, Friend & Landsbergis, 2001)
The JDC model is one of the most influential models in researching the relationship between work and health (van der Doef & Maes, 1999). It posits that although excessive job demands place strain on an individual, these demands on their own cannot account for the strain experienced (Siegriet, 2010). The JDC model states that two structural conditions of the workplace adversely impact employees’ psychological and physiological reactions (Rafferty et al., 2001). These are high demands (pressures of the workload) and low control (lacking the authority to make decisions and to use preferred skills) (Rafferty et al., 2001). Thus, the amount of strain that individuals experience in their work is determined by whether or not they have control over the demands they have to deal with (Siegrist, 2010). The diagram below taken from van der Doef and Maes (1999) is an illustration of how the interaction of the level of control and demand impact on the level of strain yielded by the job.

**Diagram 2.2**

<table>
<thead>
<tr>
<th>Low job demands</th>
<th>High job demands</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low control</td>
<td>Passive job, Low strain job</td>
</tr>
<tr>
<td>High control</td>
<td>High-strain job, Active job</td>
</tr>
</tbody>
</table>

The diagram shows that high demands and low control can lead to high strain on the individual. Empirical evidence suggests that a combination of high job demands and low job control is a significant predictor of illness and psychological strain (Bakker & Demerouti, 2007). However, there are issues that remain unresolved in this model. It leads to the inconsistent hypothesis that control can moderate the negative impact of high demands on a person’s well-being (Bakker & Demerouti, 2007). The model is also unclear on whether objective or subjective control is more important in determining the reaction to strain. This led Karasek and Theorell to extend the JDC model and develop the Demand-Control-Support (DCS) model (Siegrist, 2010).
2.9.3 The Demand-Control-Support (DCS) model
According to Rydstedt, Devereux and Sverke (2007) the DCS model is comprised of three dimensions:

- The first dimension is psychosocial work demands that are associated with the intensity of the work done by the employee. Intensity includes the workload and time pressure.

- The second dimension is control that comprises a person’s authority to make decisions at work and their capacity to carry out work tasks.

- The third dimension is the support available to the jobholder. This refers to active and emotional support from colleagues and direct supervisors.

This model assumes that the external environment determines a person’s behaviour at work. Environmental stimuli are assumed to influence emotional reactions and behaviour, while subjective factors are not considered. According to this model, jobs with a high workload, minimal control, and little support produce the most mental strain on the jobholder (Siegrist, 2010).

2.9.4 The Effort-Reward-Imbalance (ERI) model
The DCS model in combination with the ERI model has been found by numerous longitudinal studies to be a good predictor of work-related mental strain (Rydstedt et al., 2007). The ERI model is a more recent approach to the relationship between health and work. Social reciprocity is the core of this model (Siegriest, 2010). This implies that certain obligations and tasks are performed in exchange for adequate rewards, which include money, career growth, and increased self-worth (Siegriest, 2010). The effort that employees expend in their work is reciprocated by reasonable rewards from their employers. According to this model, stress reactions and associated negative feelings towards work are a result of failed reciprocity, in terms of ‘high cost-low gain’ (Siegriest, 2010). A person’s characteristics also play a role in failed contractual reciprocity. According to Siegriest (2010), people who are over committed to their work and who strive for high levels of achievement due to their unconscious need for recognition, are less exposed to failed contractual reciprocity, while those that are dependent and overwhelmed by work
commitments are exposed to failed contractual reciprocity and negative health consequences. In essence, this model combines personal characteristics with organisational features to determine health reactions.

Community caregivers are at the bottom of the existing hierarchy in the healthcare system, which may mean limited control and hence negative effects on their well-being. The epidemics that have greatly affected the country have created a shift in care provision, with most of the work falling on the lowest paid or even the unpaid (Lund, 2010). Task shifting is one of the main tenets of primary healthcare as it improves the functioning of the health system (Dawad & Jobson, 2011). Highly skilled health workers transfer core skills to health workers who are minimally trained, which enables more patients to be cared for (Dawad & Jobson, 2011).

Modern workplaces impose significant demands, especially psychological and emotional demands, on jobholders (Birgit, Gunnevi & Ann, 2012). Organisations and government departments that employ caregivers require a lot from their employees. This research study thus explored how the demands of being a CCG impact on the individual providing the care work.

2.10 Conclusion
The role that CCGs carry out in the communities has been found to be important and necessary to meet the needs of community members. The efficiency of the CCGs is influenced by the training CCGs receive, the nature of the work they carry out, as well as the support provided to them to assist them to carry out their work as well as to ensure their well-being. The self-motivation theory focuses on how the environmental and social factors of the workplace can either enhance or diminish self-motivation and healthy psychological adjustment. The Job-Demand-Control model as well as the Demand-Control-Support model indicates how an imbalance in job demand and support can lead to negative psychological effects on the employee. The Effort-Reward-Imbalance model adds on how an imbalance between efforts put into the job and reward given to the employee can lead to job dissatisfaction.
Chapter three

3 Methodology

3.1 Introduction
The chapter presents the research methodology employed for this study. It is divided into six sections: the study design, study area, study sample, data collection procedures, data analysis, and finally the ethical considerations taken into account in conducting the study.

3.2 Research design
This study adopted a qualitative approach to explore the psychological impact of community caregiving work on caregivers. A qualitative research design was appropriate because it allows for a naturalistic approach which seeks to understand phenomena in a context-specific setting (Hoepfl, 1997). This method of research allows the researcher to adopt an open and flexible approach which generates new insight on the topic (Terre Blanche, Durrheim & Kelly, 2006). The data generated in qualitative research consists of detailed responses by the study participants on the research topic and how the topic is relevant to them. A fundamental objective of this study was to understand the research phenomenon in its specific context, and a qualitative research paradigm enabled this to occur.

The aims of the study included understanding the experiences of CCGs and, in doing so, appreciating the impact that their work has on them, and identifying the resources (internal and external) that they use to cope. A qualitative method was therefore more suited to this study because qualitative designs collect in-depth information which may be difficult to achieve using quantitative methods (Hoepfl, 1997). A qualitative design enables a researcher to see the studied phenomena through the eyes of the participant (Babbie & Mouton, 2005). This approach allowed CCGs’ voices to be heard to describe their experiences, thus promoting better understanding.
3.3 Study area
KwaZulu-Natal continues to battle with high rates of HIV infection, and according to the District Health Barometer, more than 207 000 patients in the province are on ARV treatment. The study targeted the three districts of Mgungundlovu, Amajuba, and Ethekwini. The areas targeted in these districts were Pietermaritzburg, Osizweni, and KwaMashu.

Umgungundlovu district is reported to have admirable infrastructure. The capital city of KwaZulu-Natal is located in this district. It estimated population of 920 000 resides in a variety of dwellings from farmland communities, to informal settlements and upmarket urban areas. The HIV/AIDS epidemic affected the district badly, but it has been reported to be more stable as interventions have been put in place.

Amajuba District Municipality has a total population of 468 000 and covers an area of 6 900 km² in the north western corner of KwaZulu-Natal. Like many other areas in South Africa, this district is home to a large number of orphans and suffers widespread poverty. It has reported decreasing rates of HIV infection in recent years.

Ethekwini district is topographically hilly, with many valleys and canyons and almost no true coastal plain. According to the District Health Barometer (2005/06), the eThekwini metro has the highest HIV prevalence in South Africa, with prevalence of 39.9% among women attending antenatal clinics in 2005/06.

3.4 Sample
A nonprobability sampling technique was employed. In this sampling technique, the selection of participants is not dependent on the statistical principle of randomness (Durrheim & Painter, 2007). The nonprobability sampling technique used was purposive sampling, a method that depends on the availability and willingness of participants to participate. Furthermore, participants must be typical of the selected population (Martin, Durrheim & Painter, 2007). The participants in this study were purposefully selected based on the fact that they are CCGs who reside and work in KwaZulu-Natal, and who are part of the Community Based Work with Children and Youth (CBWYC) certificate programme. Approaching CCGs that are part of the
CBWYC certificate programme made for easier access to the participants and ensured the relevance of their selection as they are involved in community caregiving work.

The strength of purposive sampling is that it allows for the selection of information rich cases, in terms of this study, people with community caregiving experience in KwaZulu-Natal, who can provide in-depth information on the topic under study (Richardson, 2009). This sampling method enabled the researcher to target CCG programmes to recruit participants who were able to provide in-depth information on the psychological effects of doing community care work. Both male and female caregivers were targeted.

3.5 Recruitment procedure
The researcher contacted the personal assistant (PA) to the DSD Head of Department (HOD) to enquire about the procedures to follow when requesting gatekeeper permission. The researcher was informed by the PA that she would need to email a letter with a brief description of the research and the targeted sample (see Appendix 4) which he would then forward to the HOD. The researcher did as requested, and awaited an update. The researcher phoned the PA on numerous occasions and was told that the HOD would attend to her request. However, a new HOD and new PA were then appointed and the researcher had to start the process from scratch. Since no progress was made, the researcher contacted the DSD to enquire about how to obtain gatekeeper clearance. She was informed that the people she had been speaking to did not follow the correct procedure which was why there had been no progress. The researcher was asked to email the letter requesting gatekeeper permission and it would be sent to the appropriate people who would then send it to the HOD. This was a lengthy process, but it yielded results.

While some researchers find that gatekeepers use their control and power to deny researchers access (Renert, Russell-Mayhew & Arthur, 2013), others face the problem of gatekeepers not appreciating the relevance of the study (Renert et al., 2013), or raising ethical concerns (McAreavey & Das, 2013). In the current study, the challenges the researcher encountered were related to her request for access reaching the correct channels. Once the request was sent to the appropriate people, it took four months for gatekeeper permission to be granted.

The project officer of REPSSI was contacted and she made arrangements with the facilitators for the times and venues at which the researcher could run the focus groups.
The sample of participants who took part in the study was as follows:

**Diagram 3.1**

<table>
<thead>
<tr>
<th>AGE</th>
<th>NUMBER OF PARTICIPANTS</th>
<th>RACE</th>
<th>NUMBER OF PARTICIPANTS</th>
<th>GENDER</th>
<th>NUMBER OF PARTICIPANTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-30</td>
<td>5</td>
<td>Black African</td>
<td>28</td>
<td>Female</td>
<td>27</td>
</tr>
<tr>
<td>31-40</td>
<td>11</td>
<td>Coloured</td>
<td>0</td>
<td>Male</td>
<td>1</td>
</tr>
<tr>
<td>41-50</td>
<td>11</td>
<td>Indian/Asian</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>51-60</td>
<td>1</td>
<td>White</td>
<td>0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>YEARS OF EXPERIENCE</th>
<th>NUMBER OF PARTICIPANTS</th>
<th>AREA OF WORK</th>
<th>TYPE</th>
<th>NUMBER OF PARTICIPANTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 5 years</td>
<td>2</td>
<td>Pietermaritzburg</td>
<td>Urban</td>
<td>9</td>
</tr>
<tr>
<td>5-10 years</td>
<td>19</td>
<td>KwaMashu</td>
<td>Peri-urban</td>
<td>11</td>
</tr>
<tr>
<td>11-20 years</td>
<td>7</td>
<td>Osizweni</td>
<td>Semi-rural</td>
<td>8</td>
</tr>
</tbody>
</table>

**3.6 Data collection and instruments**

Data were collected by conducting focus groups discussions. A focus group is a method of collecting data through moderated group discussions based on participants’ views and experiences of the topic at hand (Carlsen & Glenton, 2011). Simply put, focus groups are defined as a conversation, usually involving more or less eight people, which has a purpose and focuses
on a specific topic. This data collection method emphasises interaction between the participants rather than between the moderator and participants (Carlsen & Glenton, 2011).

The CCGs that are part of the CBWCY certificate programme have weekly contact classes where they are mentored and taught. The researcher communicated with the mentors regarding suitable dates and times for the focus groups. The mentors preferred that the focus group discussions took place in the morning before they commenced class. The researcher would be introduced to the group on arrival and would then talk about the research and what participation entailed.

Three sites in three districts were visited on three different days spread over two weeks. The CCGs that took part in the study were those that arrived early for class and were therefore available. The process took two hours.

Open-ended questions were formulated to guide the focus group discussions (see Appendix 1). This ensured that the researcher remained focused on the research topic. The questions explored: what being a CCG entails; the training received by CCGs; the impact of community caregiving work; and coping mechanisms.

Focus groups provide a less tense environment for participants that are able to state their views whilst interacting with fellow participants. This allows the researcher to collect data which covers the collective experience while not losing sight of the voices and experiences of each individual participant (Terre Blanche, Durrheim & Painter, 2007). In the process, the participants develop new ideas and enmesh them with existing ideas, thus facilitating further enlightenment on their part.

There are disadvantages to focus groups. One voice could be dominant which influences the other participants to adopt or agree with his/her views. Dominant voices could also evoke fear in other participants who may be more reserved. There may also be issues of trust amongst group members. These issues were taken into consideration by the researcher and measures to counter them were put in place.

Each group member was encouraged to participate and state their views. The researcher stressed the need to respect one another and for the information shared in the group to be treated with the utmost confidentiality.
3.6.1 Focus group 1
Focus group one was run in Pietermaritzburg at a place called Mbilakahlela. The aim of this focus group and all the focus groups run during the data collection phase of this study was to gather information on the role of CCGs, the challenges they encounter in their work, the impact of these challenges, the coping skills they use and the support structures available to them.

The focus group began with the CCGs’ mentor introducing the researcher and the reason for the researcher’s presence. The researcher introduced herself and the research topic, provided details of the study and outlined what participation entailed. The researcher then opened up the floor to the CCGs to express any concerns they might have regarding participation in the study. The CCGs were initially under the impression that the researcher was a representative of the organisation that hired them. The researcher clarified that she was a full time student that had approached the REPSSI for permission to recruit a sample of CCGs to participate in her study. The CCGs were asked if they were willing to participate and were then given consent forms to complete.

The focus group discussion commenced by discussing what a CCG is and how a person becomes a CCG. The participants in this group were willing to interact and displayed no feelings of uneasiness. The discussion covered the roles of CCGs, the challenges they encounter, and the support available to them. The discussion ended with the participants being asked to recommend measures that would assist them in coping with their work.

3.6.2 Focus group 2
Focus group two was run in Ntuzuma; the CCGs who participated work in KwaMashu. The mentor introduced the researcher who discussed the research topic and what participation entailed. This group consisted of CCGs who are supervisors as well as CCGs. Participants who are not supervisors tended to look to the supervisors for answers when the researcher posed a question. The researcher encouraged all participants to state their views. Some participants did not seem to be intimidated by the presence of their supervisors and freely expressed their views. This encouraged other, quieter participants to engage in the discussion.

The topics covered in this focus group discussion were the same as those discussed in focus group one. The same schedule was used in all three focus groups.
3.6.3 Focus group 3
Focus group three was run in Osizweni, a township in Newcastle. The researcher arrived early and hence had a chance to talk to the CCGs already present while waiting for others to arriving. The session started with the researcher introducing herself to those she had not already met. She informed the participants about her research and what participation entailed. The participants were then given consent forms to complete.

The participants all appeared comfortable in the group and all contributed to the discussion. The prepared topics were all discussed starting with what a CCG does and concluding with the CCGs’ recommendations on measures that could be adopted to assist them in confronting the challenges they face in their work.

3.7 Data analysis and interpretation
The first step of data analysis was transcribing the recordings of the focus group discussions and translating from isiZulu where necessary. The transcription process involves transforming the oral interviews from the data collection stage into written data which allows for in-depth analysis to commence (Kvale, 1996).

After transcription the data was analyzed using thematic analysis. This is a qualitative method that searches for important themes that emerge in the data on the phenomena under study (Fereday, 2006). The data has to be carefully read and re-read to recognise patterns and the themes that emerge are then categorised for analysis (Fereday, 2006). While a theme may occur a number of times in the data, this does not qualify it as crucial, which is why it is important that the researcher pays attention to the data to recognise crucial themes (Braun & Clarke, 2006). This requires that the researcher have the necessary judgment skills to determine such themes.

3.8 Validity
Rigour in research is key because it contributes to the quality of the research (Morse, Barrett, Mayan, Olson & Spiers, 2002). Without objectivity, thoroughness, and consistency research becomes fiction (Morse et al., 2002). Validity is concerned with the extent to which the tools used by the researcher to gather data accurately measure the phenomena under study (Roberts &
Priest, 2006). In qualitative research, one should be conscious of not selecting and recording biased data.

To ensure the validity of the results, a research assistant was employed to assist with data collection, and transcribing and analysis of the data. The analyzed data was compared to assess if the researcher and the research assistant recoded similar results.

3.9 Reliability
In qualitative research, reliability is concerned with the trustworthiness of the study. Reliability is concerned with the extent to which the results yielded by the study are repeatable. To strengthen reliability, the data needs to be revisited and steps should be taken to reduce researcher bias. However, qualitative research rests on individual opinions and behaviours which are bound to change over time and in varying contexts (Terre Blanche et al., 2007). It thus relies more on the notion of dependability which relates to consistency in data collection and the interpretation of findings. To ensure dependability, the transcripts were read numerous times to gain a refined understanding of the data.

3.10 Generalizability
Generalizability addresses the degree to which a study’s findings can be generalized to a larger population (Polita & Beck, 2010). This study sampled CCGs from three different districts which allowed for comparison of the results across districts and for the collection of data from participants in the same line of work but working in various types of communities. It sampled information rich cases from different districts in KwaZulu-Natal to strengthen the generalizability of the findings.

3.11 Ethical considerations
It is of the utmost importance to protect the well-being of research participants (Wassenaar, 2006). The participants in this study were adults (18 years and older) and had the capacity to understand what participating entailed and the ability to consent. They were CCGs working under the CBWCY certificate programme. No specific gender was targeted and efforts were made to include both females and males in the study.
3.11.1 Confidentiality
The factors that were considered as having the potential to increase the vulnerability of the participants were that this research topic could be sensitive in nature, and that a participant might share traumatic experiences which could make them feel exposed and sad. These concerns were addressed by assuring the participants of the confidentiality of the study and that their identity would not be revealed and would not be linked to the data collected. However, they were also informed that there was a limitation on confidentiality because if sensitive issues arose that required emergency attention; their supervisors would be informed so that they could take the necessary steps to assist the participant.

Another factor that was considered was that participants may be afraid of sharing some of their experiences, especially bad experiences, as if these came to the attention of their supervisors, they might be at risk of losing their job. To address this concern, the participants were asked to sign a confidentiality agreement (see Appendix 3) that stated that no information disclosed during the focus group discussions would be disclosed elsewhere.

The participants’ identities and the information they provided during data collection were stored in a safe place, with only the researcher and her supervisor having access to it. This was done to ensure confidentiality and to make sure that the participants were not psychologically harmed in any way due to their identities and the information they provided being leaked.

3.11.2 Non-maleficence
The researcher had to approach certain authorities in order to conduct this study. These included those in charge of the CBWCY certificate programme, the REPSSI, and the University of KwaZulu-Natal. The researcher provided these bodies with all the necessary information about the study and why their organisation was being approached. A letter (see Appendix 4) detailing the study’s objectives and requesting permission to draw a sample from their organisation was sent to the CBWCY certificate programme.

The CBWCY certificate programme students meet on a weekly basis with their mentors. The researcher communicated with the mentors and the CCGs were informed of the researcher’s visit. Three sites were visited, namely KwaMashu, Pietermaritzburg, and Osizweni. Collecting data from multiple districts in KwaZulu-Natal enabled the researcher to establish if CCGs in the
province have similar experiences, which could indicate whether the results can be generalized to the broader KwaZulu-Natal CCG population.

3.11.3 Informed consent
The participants were given an informed consent form (see Appendix 3) which detailed the study’s aims and objectives (see Appendix 2) and the researcher’s particulars and contact details. No aspect of the study was kept secret from the participants. They were also verbally informed about the study to ensure that they understand what they were consenting to, and to provide them with an opportunity to ask questions should they not be clear on something.

Researchers have to uphold research ethics which not only serve the purpose of protecting the participants but ensure that there is no scientific misconduct and plagiarism (Terre Blanche, Durrheim & Painter, 2007).

3.12 Conclusion
A qualitative research method was adopted in this study since its objective was to undertake an in-depth exploration of the experiences of CCGs funded by the DSD that are part of the certificate programme offered by the REPSSI. A qualitative research method was appropriate because it afforded the participants a platform to share their experiences and how they are affected by those experiences. This method allowed the researcher to gather information on beliefs, feelings, and perceptions with regard to the psychological impact that their work has on them. A purposive sampling method was used to select information rich cases. Three focus group discussions were run to gather data on the CCGs’ experiences.
Chapter four

4 Findings

4.1 Introduction
This chapter presents the study’s findings on the experiences of CCGs from three different districts in KwaZulu-Natal. The participants were asked about the role of CCGs, the challenges they encounter in their work, how their work affects them, and the support available to them. Three focus groups were run in total, with one in Osizweni, one in KwaMashu, and one in Pietermaritzburg.

4.2 Questions posed by this research
- What is the role of the community caregivers on the DSD pay roll?
- What challenges do CCGs encounter in their work?
- How do their work experiences and challenges impact on CCGs’ psychological health?
- What support systems and coping strategies do CCGs use to cope with the demands of their work environment?

4.3 Summary of themes discussed in this chapter
The themes are presented in diagram 4.1 below to give the reader an overview of the findings before the more detailed findings are presented.

Diagram 4.1

<table>
<thead>
<tr>
<th>Role of CCGs</th>
<th>Main theme</th>
<th>Sub-theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Profiling and referrals</td>
<td></td>
<td>Care and support to people living with HIV</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Addressing the needs of vulnerable children and families</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Linking families with programmes that address poverty</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Educating family members</td>
</tr>
<tr>
<td>Challenges encountered by CCGs in their work</td>
<td>Theme</td>
<td>Sub-themes</td>
</tr>
<tr>
<td>---------------------------------------------</td>
<td>-------</td>
<td>------------</td>
</tr>
<tr>
<td>Accompanying clients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Testifying in court</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Administrative aspects</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Set target</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reporting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supervision</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Training of CCGs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Enhance skills</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limitations in applying knowledge gained</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Inconsistency of CCG roles within communities

- Demands placed on CCGs by community members
- Poorly functioning referral systems
- Community members’ perceptions of CCGs’ roles
- Lack of trust
- Funded by the government but not recognised as government employees
- CCGs’ contributions are undermined
- Racial concerns in communities

Lack of collaboration with government departments

- Shortage of forms and stationary

Lack of adequate resources to perform duties

- Sharing personal resources
- Using their own money to support their clients

Going beyond their scope of practice

- CCGs are informants
- Risks of reporting crimes
- Safety of CCGs at risk
- CCGs as HIV/AIDS workers

Community perceptions of CCGs

- Exposure to tough working conditions

Environmental factors

- Lack of career development opportunities

Departmental shortcomings

- Limitations in applying knowledge gained
### Effects of community caregiving work

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial</td>
<td>Financial constraints</td>
</tr>
<tr>
<td>Interpersonal</td>
<td>Hostility towards loved ones</td>
</tr>
<tr>
<td></td>
<td>Isolation from community and family</td>
</tr>
<tr>
<td>Intrapersonal</td>
<td>Feelings of being exploited</td>
</tr>
<tr>
<td></td>
<td>Feelings of being unimportant</td>
</tr>
<tr>
<td></td>
<td>Feelings of inadequacy</td>
</tr>
<tr>
<td></td>
<td>Need to protect their integrity</td>
</tr>
<tr>
<td>Psychological</td>
<td>Preoccupation with clients’ problems</td>
</tr>
<tr>
<td></td>
<td>Anxiety about their safety</td>
</tr>
<tr>
<td></td>
<td>Sleeplessness</td>
</tr>
</tbody>
</table>

### Support systems and coping strategies

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support available to CCGs</td>
<td>Lack of sufficient support</td>
</tr>
<tr>
<td>Coping strategies employed by CCGs</td>
<td>Need for financial gain</td>
</tr>
<tr>
<td></td>
<td>Interpersonal relations</td>
</tr>
<tr>
<td></td>
<td>Intrapersonal coping</td>
</tr>
<tr>
<td></td>
<td>The need for psychological support</td>
</tr>
</tbody>
</table>

### 4.4 Roles of CCGs

#### 4.4.1 Profiling and referring

The CCGs stated that their work mainly involves profiling and referrals. When they arrive at a home, they assess which needs are not being met, and refer to appropriate departments that could assist the family.

*P1: “I look at the needs of the whole home.... I then profile, after profiling those cases I have found as a caregiver I then refer.” FG1*

One of the participants shared the details of her role as a CCG. She said that she looks after the needs of the whole household. She added that she also sees to the health needs of her
clients by assisting households with ill family members. In all the focus groups, it was agreed that CCGs make many referrals. While, on the surface it may appear that CCGs’ work is limited to profiling and referrals, the discussions revealed that much more is involved. It also became apparent that CCGs perform more tasks than are expected of them.

During the data collection phase, two categories of CCGs were identified, those funded by the DOH and CCGs funded by the DSD. The participants stated that, in their understanding, DOH CCGs take care of the health needs of community members because they are provided with the necessary tools and knowledge to carry out this task.

*P:* “They (referring to DOH CCGs) deal a lot with people who are ill only. They deal with persons who are ill and immunization cards for children.” FG1

According to the participants, bedridden and chronically ill people and any other health issues are the responsibility of DOH CCGs, whereas CCGs funded by the DSD take care of community members’ social welfare needs.

*P:* “We deal with vulnerables, children with no certificates, who do not receive grant money, foster children, and ID documents, then there is also child support grants.” FG1

The data on the different roles performed by CCGs suggest that they go beyond the scope of their duty. The work done by CCGs that goes beyond profiling and referrals is discussed below.

### 4.4.2 Care and support to people living with HIV

The participants highlighted that part of their role as CCGs is to provide support for people living with HIV and to refer them to appropriate service providers.

*P6:* “People’s needs differ. Others you find them ill you find that they need to disclose (their status) to you”. FG2

Participant 6 shared that CCGs need to create a comfortable relationship with their clients so that the clients feel secure to share their HIV status.

*P:* “Another person you may find them sick, you find that they need to disclose to you. You maybe ask them questions that are close to them. Maybe have they tested and status..."
did they get. You make them aware that since it is just the two of you talking, it is not something that will be talked about to other people. We make sure that this which you are discussing is between him/her and you.” FG2

This extract highlights that reminding clients that the information they share with CCGs is confidential encourages them to disclose whether or not they have tested for HIV and their status. The participant added that CCGs need to ask appropriate questions to facilitate such disclosure. Participants across the focus groups noted that some community members conceal their status even from family members, and this hinders access to appropriate support. They stressed the importance of having a caring supportive relationship with their clients, which eases the disclosure process. However, it is not always easy to build such a relationship due to some of the challenges posed by the work carried out by CCGs.

4.4.3 Addressing the needs of vulnerable children and families
The participants reported that they mainly work with families that are exposed to poverty which renders these families vulnerable to a variety of risks. One of the CCGs’ roles is to address these vulnerabilities and direct families to channels that can offer assistance.

P3: “We deal with vulnerables, children with no certificates, who do not receive grant money, foster children, ID books, and then there is child support grants.” FG1

This extract shows that CCGs’ clients have different needs. The communities in which the CCGs work are poverty stricken and many people do not have identity documents or birth certificates and hence cannot register for grants. This is where CCGs’ referral work comes in. They commence the process which leads to their clients’ needs being addressed.

According to the participants, some families are receiving grants but are still vulnerable to other challenges brought about by their socioeconomic situation.

P: “The communities we work in, we could say they are poverty stricken, HIV/AIDS is rife, there is teenage pregnancy, substance abuse and alcohol abuse.” FG3

According to the participants in all focus groups, poverty, HIV/AIDS, and substance abuse are major issues in the communities within which they work and live. Their clients’ vulnerabilities mainly relate to these issues. They noted that programmes to address these
challenges in the communities where they work and reside would bring about positive change. This requires collaboration between the CCG programmes and departments such as Home Affairs, social services, and the South African Police Services.

4.4.4 Linking families with programmes that alleviate poverty
It has been highlighted that, while CCGs work with families of different economic status, most of their clients are poverty stricken. In addressing poverty, CCGs reported that they refer families to organisations or departments that can assist them.

P: “What links us as CCGs and organisations……we enter a home and encounter that there are this many orphans that do not receive this… so we take that information to organisation.” FG2

For example, where a child is not receiving a grant, the caregiver would link the child with the South African Social Security Agency (SASSA) for assistance. The participants also reported that their work includes delivering food parcels.

P: “When you show up, you are a food parcel……when you appear a food parcel appears.” FG1

The above extract highlights that community members expect CCGs to deliver tangible goods such as food parcels. The participants stated that when they brought something tangible, they were more appreciated. This suggests that, since most of their work involves referrals which do not represent tangible goods, their visits might be undervalued by clients.

To ease the process of linking community members with programmes that address their needs, war rooms have been established that the CCGs attend once a month. The participants described these war rooms as a meeting where CCGs meet with various departments to share their challenging cases and refer them to the appropriate department.

P: “The war room is where there are various departments there, when a problem is taken there to the war room then that department then it is easy for it to take the case and to handle that problem.” FG3
This participant stated that war rooms are an easy way to get cases to different departments, and are a space where caregivers receive input from various departments about the cases they report to the war room. However, the CCGs noted that being able to easily and appropriately refer cases does not always mean that their clients will receive the help they need in a short period of time. This means they need to visit their clients regularly to find out if a certain department has assisted them. They noted that clients become irritated with them if they do not deliver positive results.

4.4.5 Educating family members
The participants stated that information sharing is a vital part of their work. Creating awareness helps to prevent the challenges facing communities from escalating. Information sharing also helps to empower people to cope on their own.

\[P: \text{“CCGs when they enter a home where there is a sick person their job is to educate at least one member of the home”}. \text{FG2}\]

The participants noted that when an ill person’s family member is taught how to take care of them, the family is better able to cope.

4.4.6 Accompanying clients
The participants also noted that they accompany their clients to the various departments that can assist in meeting their needs.

\[P: \text{“You find that you left maybe you had five cases. Some you have to take to Home Affairs, and other departments. At the end you will sit in one place for the whole day..... You see a month may go by because of these queues that you stand in.” FG1}\]

This extract shows that at times, CCGs struggle to cope with their case load as they can spend a great deal of time standing in queues at various departments. The participants reported that sometimes they have to wake up at three in the morning in order to be at the front of the queue. They sacrifice their sleep to help their clients.

4.4.7 Testifying in court
The participants stated that at times they have to testify in court especially when there is a rape case in the ward in which they work. This exposes them and their families to certain risks, and thus raises their stress levels.
4.5 Administrative duties of CCGs

To ensure that they deliver appropriate services in the community, administrative tasks are part of CCGs’ work.

4.5.1 Set target of homes that should be visited

The participants reported that they need to visit a set target of 60 homes per month.

P7: “It is written that I have to visit 60 homes a month, but I try to check on her at church, or twice when I pass by her house.” FG2

This participant shared how CCGs arrange their daily visits to ensure that they meet their monthly target. All the focus groups noted that clients expect CCGs to visit them daily, which is not possible given the set target, so CCGs juggle how they meet the target while reviewing some homes.

The caregivers stated there have to fill in forms which they use to assess and profile a household. When visiting a home for the first time, they construct a profile that reflects family members’ vulnerabilities.

P: “You are told to profile a home, you profile a home. You write in the form that the house they live in is skewed.” FG2

Every problem identified should be recorded and referred for assistance. Caregivers need to ensure that they have forms and that these are completed for every new case.

P: “We even take out our own money when they say there are no papers in the office. What can we do? We need these forms.” FG3

When the office that supplies them with the forms is out of stock, some CCGs use their own funds to print more forms because they cannot do their work without all the necessary documents.
4.5.2 Supervision provided to CCGs by more experienced CCGs

CCGs with more experience in the field are selected to supervise other CCGs. The participants reported that supervisors ensure that CCGs perform their duties, offer help with difficult cases, and ensure that CCG’s administrative work is up-to-date.

P3: “Let me talk about myself. I and this lady next to me are supervisors, we supervise. You have to monitor..... has the CCG visited three or maybe four a day?” FG2

This participant shared how she ensures that the CCGs she supervises meet their monthly target. She added that she manages their attendance and offers support. The supervisor’s role extends to assisting CCGs with difficult cases.

P: “A boy locked her in the house and left, so I took that case and reported to my supervisor.” FG3

In this case, a young man was neglecting his bedridden mother, locking her in her home and leaving her alone. As the young man was an acquaintance of the CCG, reporting this neglect was not easy.

4.6 Training of CCGs

The themes that emerged from the data on the training of CCGs are discussed below.

4.6.1 Enhance skills

The study participants felt that they are adequately trained for the work they carry out in communities. They said that their training is more than sufficient and they feel confident about their ability to do their work. Their skills are continuously developed in the teaching sessions which they attend once a week.

P2: “Since we have been selected to be community caregivers...., workshops at which we are trained are a regular thing.” FG2

P6: “We receive training to be able to face challenges.” FG3
Participants in all the focus groups agreed that they receive adequate training. In addition to their weekly contact sessions, they attend workshops to further develop their skills. They feel confident about their knowledge and ability to help community members.

*P1:* “We have just come from a 3 week workshop, it was a very big training that the department funded.” FG2

The CCGs who are supervisors also attend workshops for further training. The above extract is from a participant who is a supervisor who noted the extensive training they receive and the prestige attached to it. Thus, the CCGs do not lack training and feel very competent in their work.

4.7 Challenges encountered by CCGs in their work

4.7.1 Inconsistency of CCGs’ roles within communities

As noted earlier, the participants said that their work mainly involves profiling and referrals. Thus, they arrive at a home, assess which needs are not met, and refer the family to appropriate departments that could assist them. The CCGs that are employed by the DSD said that their role does not include taking care of the health needs of community members. Rather, they assist with social welfare needs. However, they find themselves caring for health needs because they cannot ignore a person who is suffering.

*P:* “Community care givers are actually different, there are community care givers that work under department of health and there are those under DSD, but when we arrive at a person’s home and we find problems there, we do not say this is for Health or this is for whoever. We take over whatever it is that we find in this home.” FG1

This participant explained that while they are employed by a certain department to cater for certain needs in the community, they do not simply ignore other needs that may require the intervention of a DOH CCG. The participants in all focus groups agreed that they try to assist community members regardless of whether their problem falls within their scope of practice.
The participants also noted that community members expect a lot from CCGs. They find themselves working constantly and giving time to the community beyond that which the DSD expects of them.

P: “They expect that maybe come in and do everything, when actually CCGs when they enter a home where there is a sick person their job is to educate at least one member of the home”. FG2

This excerpt shows that family members have a different concept of what a CCG and their scope of practice is. The CCGs explained that their work includes educating family members on how to care for those who are ill or bed ridden. They noted that they are expected to visit 60 homes a month and therefore have to share knowledge in order to ensure that the families they visit know how to move forward in caring for the sick. However, some community members do not see things this way. They expect the CCG to visit daily to cook, clean, and bathe and feed the sick. This is beyond their capacity as they have other homes to visit. The CCGs that participated in this study do not view their role as caring for sick community members.

P: “We at DSD do not touch a person, it is Health that touches a person” FG3

Thus, while the participants do not define their role as practically catering for the needs of ill clients, family members expect more from CCGs than providing them with knowledge.

P: “You arrive there and they have to take pills….you try to cook something small, a bit of maize meal so they can get...We can’t do that every day because even people who earn forty or twenty thousand wouldn’t be able to bear that.” FG2

This participant noted that clients need a full stomach to take their medication. However, CCGs cannot do this every day as they have to meet their monthly target and their stipend is too small. It appears that some families neglect their ill relatives and hence the task of tending to them falls on the caregiver. Even though CCGs feel overwhelmed by this situation, they continue to perform tasks beyond their scope of practice. It appears that they do this to reinforce their value as CCGs, to assist clients who are also neighbours that they have close relations with, and to make a positive difference in their community.
4.7.2 Lack of collaboration
As noted earlier, the participants said that their work mainly involves profiling and referrals to different departments that can assist community members to fulfill their needs. This requires a good working relationship between themselves and different departments.

4.7.2.1 Poorly functioning referral system
The CCGs stated that they refer their clients to organisations within DSD such as SASSA and outside DSD such as SAPS, Home Affairs, and clinics. To ease the referral process and to assist CCGs with cases which they have not referred because they are not certain of the appropriate department, structures such as war rooms have been established.

4.7.2.2 Government structures put in place to facilitate collaboration
In the war rooms different departments meet monthly with CCGs to discuss cases and to allow caregivers to express the challenges encountered and receive assistance. This is also the space where the CCGs refer their cases.

   \[P: \text{“That department arrives and takes it’s problem, a problem left by the CCG here. If it is home affairs they take, if it is health they take, if it is social development they take because all departments are present at the war room.”} \text{ FG2} \]

This participant explained how the war rooms should function. All the various departmental representatives are expected to attend so that they can receive and discuss client referrals. While this is a potentially effective strategy to ensure service delivery, the war rooms are not functioning as they should.

   \[P5: \text{“Firstly at the war room, the departments do not arrive, they do not all arrive, maybe it happens that only two arrive but you find that there are many cases which need the different departments”}. \text{ FG1} \]

At the time when this point was raised about war rooms, the participants in FG1 were talking over each other to express their frustration with the poor attendance at war rooms. Participant 5 explained that not all the departments that are required to attend arrive at the war room meetings; hence, not all cases are referred to the appropriate department.

   \[P7: \text{“They help sometimes (referring to the war rooms), but it sometimes requires you as a CCG to go to the department” (to find out the progress of a case). FG2} \]
Delayed intervention is experienced even within a department. The CCGs expressed frustration with DSD employees who do not work collaboratively with them; hence, service delivery is delayed and clients get frustrated with CCGs.

4.7.2.3 **Lack of collaboration within the department**
The CCGs said that they do a lot of referral work, and although there are successful cases there are many that go for lengthy periods without being attended to or resolved. This creates the impression that they are not doing their job properly.

    P4: “It is because there is nothing that we come with. We came today, another was there the previous day, everything, all these years since this thing of CCGs started there is that home where when you have entered you are told, my child I have been applying, my child I have been doing this and this but until today look I am still staying in this house”. FG1

Participant 4 in FG1 cited a family that has been waiting for a Reconstruction and Development Programme (RDP) house for a number of years. Many CCGs have visited this home over the years and have referred the case but the family has still not received a house. Community members initially put their hope in CCGs but when they find that even after numerous visits from CCGs their problems are not attended to, they begin to doubt CCGs’ abilities and become suspicious of what they are doing with their personal documents. Those who have been disappointed by the lack of intervention tell others about their negative experiences and hence some community members do not want to allow CCGs into their home.

4.7.2.4 **Funded by the government but not recognised as government employees**
The participants stated that they are not given any recognition by any department or organisation. They added that they would like to be recognised as government employees, as opposed to the treatment they currently receive from employees at some institutions.

    P: “Others approach us and say ‘I know if I come to you I will get help, you have easy access’ but they do not know. You know when we go to SASSA we stand in the queue like everyone else….we are nothing.” FG1

The participants noted that community members are under the impression that CCGs have easier access to resources and will therefore ensure that their problems are attended to. The participant quoted above said that a client that needed to register for a grant approached the caregiver for
assistance in the hopes that when the CCG was involved, this would speed up the process. However, the participants shared that their involvement as caregivers does not speed up any process, because they wake up early to accompany clients and wait in queues with their clients and sometimes even get sent back.

\[\text{P1: “You stand in queues at the clinic; you find that community caregivers are not recognised. Community care givers are not respected, they are not given that role that they deserve seeing as they are people who work committedly in the community.” FG2}\]

This participant noted that other professions do not view them as colleagues or government employees but as ordinary people who have no status.

The CCGs reported that the government does not give them any benefits because they are not government employees even though they are funded by the government. For them, this is further indication of how devalued they are.

\[\text{P4: “Let’s say you supposed to go see the doctor, let us not always be going to clinics.” FG3}\]

Participant 4 in focus group three noted that government employees have the option of medical aid. As caregivers who serve the community, they would also like to receive the benefits on offer to government employees. They shared that they feel awkward sitting in queues alongside their clients.

4.7.2.5 Lack of a collaborative relationship between CCGs and the community
A cooperative relationship is lacking not only between CCGs and government employees, but between CCGs and the community members that they assist. The CCGs blame poorly functioning referral systems for negatively impacting their relationship with community members.

4.7.3 Community members’ poor perceptions of CCG roles
CCGs noted that that can only offer limited assistance; they can only refer or assist the client with the application process and have no control over if and when the service will be delivered.
P: “Another cause is that we are limited, we have limitations, we only refer, yes we just referring the cases only, and then you can’t, that you skip cases you have limitations at your work”. FG3

P: “It ends up looking like it is our fault, or that we do not know our work properly.” FG3

While the participants noted that not all cases go unnoticed and unattended to, a lot more could be done. They said that community members get frustrated with them because they have direct access to them. While they have done the work required to kick start the process to assist clients, delays occur at the levels above them. Not all CCG interventions have negative results; the caregivers reported that their interventions have helped community members receive the assistance they needed. Community members who hear that their neighbor received assistance because a CCG intervened approach CCGs for assistance. However, the participants felt that there are too few cases where clients receive the resources they need and much remains to be done.

4.7.3.1 Lack of trust
There is mistrust between CCGs and some community members. The CCGs stated that the main reasons why community members do not trust them are firstly, because they have witnessed many people that have placed their hope in CCGs remaining unassisted, and secondly, because they work in the communities within which they reside so neighbours fear that CCGs may breach confidentiality.

P2: “[mm] ehe there are those challenges that when you work in that ward your neighbor does not trust you, they do not want to tell you everything.” FG3

While the participants noted that working in the neighborhood where they live is beneficial because it reduces transport costs, it has many disadvantages. One is that neighbours are not completely transparent with CCGs. Participant 2 noted that neighbours will downplay the direness of their circumstances or withhold information because they do not trust the CCG.

P5: “Another thing is that it is difficult for them to release their personal details because they know that there is no help that they receive”. FG1
This lack of trust hinders CCGs’ work. The participants stated that they understand that it can be difficult to trust someone when you do not see the results of their work. With many clients still waiting for the results of CCG intervention it is hard for new clients to believe that their situation will be any different.

4.7.3.2 **CCGs’ contributions are continuously undermined**

The participants said that they feel constantly undermined and devalued not only by community members but by some of employees at the departments they work with. They noted that their work requires love, care, patience and the desire to help others. While the CCGs felt that they were provided with enough knowledge to assist the community in the best way possible, they are viewed as lacking knowledge and of no use.

\[ P3: \text{“The biggest issue is that our communities do not receive us appropriately, their view is that the knowledge we have is very little. Even when you arrive at their homes you can see that do not trust your explanations, they do not receive us well.”} \text{FG3} \]

According to the participants, they are continuously second guessed by community members. Participant 3 from focus group three said that when they arrive at a home to assist the family, family members challenge CCGs’ responses to their questions.

\[ P: \text{“Eyi they used to treat us well before, two years back nje eyi we were treated well. Now that just give you a look, we are useless things to them”}. \text{FG1} \]

The above excerpt shows that this was not always the case. While the majority of the participants said that they feel devalued by community members, this participant noted that a few years back, communities valued the service provided by CCGs. The situation changed when people witnessed fellow community members who put their hopes in CCGs receiving no assistance.

4.7.3.3 **Racial concerns in communities**

The participants reported that some community members of a different race from that of the CCG refuse to seek assistance.

\[ P8: \text{“Certain races isolate themselves, they do not want to come ask for help from you because you are black or because you are a CCG something that is not valuable”}. \text{FG1} \]
Participant 8 in focus group one said that, while it might appear at times that CCGs only assist their own race group and neglect others races, members of other race groups do not want to seek help from CCGs either because of their race or because CCGs are generally looked down on.

4.7.4 Lack of adequate resources to perform their duties
In addition to not receiving many benefits, the CCGs said that they are not provided with adequate resources to carry out their work. They find themselves using their own money to ensure that they perform their duties.

4.7.4.1 Shortage of forms and stationary
The participants reported that in order to profile and refer clients, they need to fill in the necessary documentation. They need stationary and the necessary forms to complete their daily work. These resources are not always available.

P: “We even take out our own money when they say there are no papers in the office. What can we do? We need these forms.” FG3

This participant said that CCGs are often told that the departmental office has run out of printing paper. In such circumstances they use their own money to photocopy the forms elsewhere because they need them for their work.

P5: “Again there are things that assist us to do our work because we are writing all the time. They receive stationary at the office, why we not provided.” FG3

Participant 5 noted that social workers are provided with stationary to assist them with their work. She questioned why CCGs are not provided with the same because they also serve the community’s needs. A lack of resources to perform their duties has negative effects because it requires them to use their own money; CCGs regard this as further indication of how devalued they are.
4.7.5 Going beyond their scope of practice

4.7.5.1 Sharing personal resources
The CCGs also find themselves taking money from their pockets to give to those they are assisting. They stated that while they themselves do not have much, they give from the little they have because they can relate to the challenges that their clients are experiencing.

P: “In the communities we work in you see most of them you see others are poor, dying from poverty. You find that sometimes you end up taking spinach from your own home to that client of yours who you can see that it is very difficult, maybe you end up taking with two potatoes as well”. FG2

The participants provided many examples of situations like the one described above where they use their own resources to assist clients. In the above extract, the participant was speaking about a client that is on treatment and needs to take medication after a meal. Since a CCG cannot administer treatment to a hungry person, they take food from their own homes and give it to their clients.

4.7.5.2 Using their own money to support their clients
In addition to sharing their resources with clients, CCGs use their own money to assist clients.

P: “This 1.5 that we are earning that is little, we have to use it to pay for people’s transport fees.” FG1

Participants shared that when their clients need to go to SASSA or Home Affairs to apply for grants or identity cards but do not have money for transport, they pay from their own pocket so that the client can receive the help they need.

4.7.6 Ill-informed perceptions of CCGs
Some community members misinterpret some of the roles carried out by CCGs. This poses a challenge for CCGs when their interventions are misinterpreted as maliciousness and they feel their safety is jeopardized.

4.7.6.1 CCGs are informants
The participants noted that CCGs are expected to intervene in numerous situations because their work entails ensuring the well-being of the community. This is not always easy because they find themselves in difficult situations where their help is misinterpreted as vindictiveness.
P: “You know maybe in homes you find certain situations, like me nje one day I was helping. There is this other lady who is bed ridden, they lock her in the house, she cannot wake up, she is given water, everything is done for her. A boy locked her in the house and left, so I took that case and reported to my supervisor, my supervisor arrived and found that the woman is indeed locked in, she is lying down, and finding it difficult to breathe. Suddenly the boy came back and called the ambulance for his mother. The boss called on my phone and spoke to the boy. The boy in turn said I’m trying to get him arrested. You see that it is no longer nice it ended up not being nice until today it is not like before.”

FG3

This extract shows how a CCG’s good relationship with her neighbour was negatively affected by carrying out her duties. She and the son of the bedridden lady used to check up on each other and when coming across each other on the street would engage in lengthy conversations. They had a good relationship as neighbours until she reported that this young man would lock his bedridden mother in the house. The CCG found his behaviour neglectful and hence reported it. The young man interpreted this as an attempt to get him arrested. Since this incident they no longer speak to each other.

4.7.6.2  CCGs reporting to the police

The participants said that part of their work includes reporting crime or abuse in their communities. This poses a challenge because they would be reporting people fellow community members.

P: “The police a quick, they are quick. They arrest and say that you informed them. The police do not lie, they say who told them. You see maybe you are now in trouble.”  FG2

This participant shared that when CCGs witness illegal behavior such as the selling of illegal substances like marijuana, they have to report it to the police because it poses a threat to the community. While it is good that the police are quick to intervene, they tell community members who reported the crime, jeopardizing CCGs’ safety.
4.7.6.3  **CCGs’ safety is threatened**

Community caregivers feel that their safety is put at risk by some of the duties that they have to perform. Tasks such as testifying in court leave CCGs feeling vulnerable to violent acts from community members whom they testified against.

*P: “It is not safe to go and testify in court when you live in the very same community, you end up having enemies in your own community.” FG1.*

The participants in FG1 stated that they have to testify in court at times. The other two focus groups did not cite testifying as an issue that creates discord but that reporting to their supervisors and to the authorities was an issue. In the extract above, the participant shares that when someone commits an illegal act in the community, the neighbours will call them because they are CCGs, and they are expected to report it, and sometimes testify at a later stage. This results in CCGs becoming the enemy.

*P: “Neighbors tell you that this person has raped a child, take steps because you have been told of the case....You think of the money, you think of your children, you think for your life, and you just go crazy before going there. You go there you are already not emotionally okay.” FG1*

This participant noted that CCGs sometimes weigh the risks and benefits of reporting or intervening when neighbours call them.

In terms of their safety, the participants expressed great concern because they felt that their work sometimes puts them in danger. They were vulnerable to violent action from community members who felt betrayed by their reporting.

*P: “Last week, boys were carrying knives, throwing knives at each other, saying here are these social workers.” FG1*

In the above incident, CCGs were walking home after a war room meeting and came across young men who had experienced CCGs reporting their violent behavior. These young men threw knifes at each other to scare the CCGs.

*P: “You end up being the enemy, because you have to say if something is not right, you have to report it.” FG2*
While the participants noted that their interventions are not always well received; they cannot sit back and pretend to not see what is going on. Some CCGs admitted to turning a blind eye to certain situations as they felt that they were putting their lives at risk for a small salary. It made it harder that these are people they have known for years because they reside in the same area.

4.7.6.4  **CCGs being stigmatised because of the perception that they are HIV/AIDS workers**

Stigma is a major issue, especially towards people who suffer from certain illnesses. The HIV/AIDS epidemic rekindled enthusiasm for CCGs. However, the participants noted that CCGs are seen as helping people who suffer from HIV-related illnesses. This results in community members being afraid of being associated with CCGs because this would imply that they are ill or that one of their family members is ill.

_P: “The communities in which we work, we could say they are suffering from poverty, HIV and AIDS, there is teenage pregnancy, substance abuse and alcohol abuse. So nje you are going to help a person who is infected. The person will ask you that what is it that you think they have since you are coming to them.” FG3_

Since the CCGs reside in the communities within which they work, they hear from community members that a certain household needs help with food parcels or assistance with a bedridden person, but families sometimes refuse to accept their help. A participant in FG3 explains in the above extract that family members would ask CCGs what they think they are suffering from, and question the purpose of their visit. Community members become defensive and offended by the caregiver’s visit. Being visited by a CCG is an embarrassment for some community members.

_P: “In some homes you enter and you can see that this person is unwell, but they just tell you that they are fine. There is that stigma that there this person always visiting this home and we know the kind of people this person works with you understand.” FG3_

The participants stated that in some instances they could see when visiting a household that they need assistance. Some members of the community recognise that they need help from CCGs, but pride overcomes them. They do not want their neighbours to look down on them because they have a sick family member or are receiving a food parcel.
4.7.7 Environmental factors
Environmental factors pose a challenge for CCGs in their work because they expose them to conditions which make them vulnerable.

4.7.7.1 Exposure to tough working conditions
The places that CCGs have to walk through, and hostility from family members add to their feelings of not being safe. They said that they are viewed as people who have no worth and they often feel that they are not taken seriously. They felt that their safety is not always a priority for stakeholders. The conditions they endure in order to perform their duties are not safe.

P: “We CCGs we walk, walk in bushes, go until we arrive [pause] we walk in these bushes, you have to go because you said you would return to that house” FG1

The participants said that because they are the least skilled and the lowest paid workers, they have no means of transport and have to walk. They compared themselves to social workers who use government vehicles to make home visits. The participants added that even when they have experienced the bad conditions they have to endure to reach certain homes, they have no choice but to return, as it is part of their job.

P: “We walked until we almost got bitten by snakes, we get chased by dogs. We do this work but at the same time it is not going anywhere, because people are not getting helped, so we are just going to be a nuisance to people, and others do not open for us. They see you coming and they close their doors.” FG1

The CCGs continue to visit the homes of community members even though some families have not received the assistance they require. Some families have resorted to not letting the CCG in and closing their door when they see a CCG approaching their home. In such instances, CCGs endure unfavourable conditions to reach the home, only to find that some families will not give them the opportunity to render their services.

The second focus group included supervisors who are also CCGs, but oversee other caregivers. One supervisor said that they are cognizant of CCGs’ working conditions and tried to address certain situations.
Participant 10 briskly responding to this participant, stating that regardless of the conditions, they are expected to work. The majority of the group agreed with participant 10 while some remained silent.

P10: “Sorry, can I please comment. Where we work it is not like that. We work even when it is pouring, no matter what the weather condition is. We have to go to work, you have to sign in and when you come back at 4pm you sign and go home”. FG2

The harsh conditions in which CCGs work was a concern expressed across all focus groups. It appears that conditions differ for CCGs working in different wards. However, what remained constant was that they are all treated with hostility at times and have to walk in areas that are not safe.

4.7.8 Departmental shortcomings

4.7.8.1 Lack of career development opportunities
The participants said that they feel stuck in their community caregiving work. They felt that there is no progress in the lives of CCGs, because they enter the job with a stipend of R1 600 and do not advance to other jobs that pay more or have higher prestige. Some participants stated that they had been doing this work for more than ten years but, regardless of the training received and knowledge gained, they are still caregivers earning a stipend.

P: “They should also do that with us. Let’s say since REPSSI has taken us mmm, they must teach us, so we could get certificates, they should place us where they can, because now it is not helpful for them to train us and just leave us like that. We are just in their data base.” FG1

This participant felt that the certificate course that they are part of should lead to something other than remaining a CCG earning a stipend.
P: “There are always bursaries, always learnerships (laughter in background) so you think that, we should actually be the first in line when there is an opportunity, we should be given opportunity to apply and try so that we too could have the optimism to move forward *speaks in low voice* but now ey…” FG1

The participants felt that they should be given the opportunity to study further and secure better employment. They constantly compared themselves to CCGs who work under DOH whom they felt are always given bursaries to develop further, thus making more progress than they do.

P: “REPSSI will tell you to your face that they will not place us anywhere, whereas Health is being taught, and they get work.” FG1

They added that DOH CCGs start off as caregivers but advance into nutrition and nursing. Because they are given opportunities to study, they find more secure employment.

4.7.8.2 Limitations in applying knowledge gained
The participants expressed that even though they are equipped with a lot of knowledge and their skills are continuously developed, they are limited in what they are allowed to do in the field. They cited a large discrepancy in terms of how they apply themselves in theory compared to how they apply themselves when dealing with community members.

P: “...At work your supervisors told you not supposed to intervene, you just refer. You can’t now apply the work you learn.” FG3

This caregiver narrated how she intervened in a case where a child was not attending school. She spoke to the family and the staff at the local school to find out why the child was no longer attending school. She added that the material they are taught teaches them to actively intervene. Her supervisor felt that she should have referred the case to a social worker.

4.8 Effects of community caregiving work
4.8.1 Financial constraints
The participants reported that they come from similar backgrounds to those of their clients. They receive a stipend of R1 600 which is little considering that they also use this money to assist their clients where they can.
Participant three shared how CCGs struggle to provide for their families. Their children cannot afford smart phones; they can barely afford essentials for their schooling such as calculators. This leaves CCGs frustrated because they work hard without adequate financial gain.

4.8.2 Interpersonal effects of caregiving work

4.8.2.1 Hostility towards loved ones
The participants reported that the circumstances they endure at work results in them being hostile towards their loved ones.

P: “You become very aggressive at home. The children you are raising, you do not raise them the proper way because you are full of aggression” FG1

They shared how they have to humble themselves in order to carry out their work and deal with other people’s hostility. They do not express their frustration to clients or departmental employees, possibly because they value their work and would not want to jeopardize it, or because they value their income, or feel inferior due to community members and government employees’ perceptions of their status. As a result, they end up full of aggression that they may take out on their family members.

4.8.2.2 Isolation from community and family
The participants noted that community caregiving work leads to them feeling so tired that they lack the attention and vigour to spend time with their families.

P: “You get home and you are tired, you cannot pay attention to your child, you are tired, you do not have time for your child.” FG3

Furthermore, community members invade their off duty time and visit them on weekends to report problems.
The participants added that when they report criminal activities they become the enemy and are thus isolated.

\[ P: \text{“You end up being the enemy because you have to say when something is not right and report it.” FG2} \]

The participants noted that this results in some of their neighbours no longer interacting with them. Due to such pressure, some CCGs turn a blind eye to criminal activities. This could be due to the fact that they do not feel that they are valued at work or appropriately rewarded; thus, they are unwilling to jeopardize their relationships with their neighbours or put the lives of their families at risk.

4.8.3 Intrapersonal

4.8.3.1 Feelings of being exploited

The participants expressed feelings of being exploited by stakeholders. They felt that they are being used to attract funding that benefits management.

\[ P: \text{“They expect to benefit from us.” FG1} \]

\[ P: \text{“You will carry on earning that twenty cent that you get. You are only a tool that brings money that they take pictures of.” FG2} \]

Speaking of funding, the participants stated that they are sometimes given uniforms to wear and asked to tend someone’s garden, and pictures are taken as part of a fundraising drive. However, the funding received is not used to increase their salaries or benefits and they thus feel exploited.

4.8.3.2 Feelings of being unimportant

The participants reported that CCGs sometimes find themselves in situations that leave them feeling unimportant.

\[ P: \text{“We are nothing.” FG1} \]

They cited situations that endanger CCGs’ lives such as reporting abuse or drug selling in the neighbourhood. The CCGs reported that they feel helpless because should they report or ignore the crimes that need reporting, there will be consequences of either being the enemy in their
community or their employment may be threatened. Their safety is not considered because they are not regarded as important.

4.8.3.3 **Feeling inadequate**
The participants stated that some of their clients go for years without receiving help even though a caregiver constantly visits the home.

   *P4: “It is because there is nothing that we come with. We came today, another was there the previous day, everything, all these years since this thing of CCGs started there is that home where when you have entered <you are told>, my child I have been applying, my child I have been doing this and this but until today look I am still staying in this house”*. FG1

Participant 4 in FG1 shared the story of a family that has been waiting for an RDP house for a number of years. Many CCGs have visited this home over the years and have referred the case but the family has still not received a house.

4.8.3.4 **Need to protect their integrity**
The participants reported that they end up using their own resources to assist their clients in order to raise clients’ faith in them and in their reliability.

   *P: “We end up using our own money”. FG3*

The majority of the participants reported that they have used their own money to assist their clients in many instances because CCGs are viewed as inadequate.

4.8.4 **Psychological effects of community caregiving work**
The caregivers noted that the work they do on a daily basis greatly affects them. They become so absorbed in other people’s problems that it affects their emotional state. They stated that when interventions they have put in place do not yield results, they are negatively affected as they become consumed by wanting to see progress. They lose losing sleep thinking about their client’s problems and worrying about their own safety because they are often regarded as enemies due to the work they do.
4.8.4.1  **Preoccupation with clients’ problems**

The participants reported that they spend a great deal of their time thinking about the problems their clients are having and how they could assist them. Even when they are not at work they continue to think about work-related issues. The participants reported that their work takes up all their time because even when they leave work they take the clients’ problems home with them.

*P: “Eeh, I would say the challenges we face do not sit well with me, because even when I arrive home, and I’m trying to do my self-care, there is that thing that disturbance in you oh my God.” FG2*

This participant shared that, even when she tries self-care, the challenges linger in the back of her mind.

*P: “It affects us because you end up taking someone’s problem and making it your own, it ends up being on your shoulders. When actually, when you deliver it at work you should leave it there. When you go home you should leave fine, but it doesn’t happen because you take it and wear it and it becomes yours. You end up talking about it at home, that you know I have come across this sort of problem that is like this and this and this, it worries me, but I do not know how I will help this person.” FG3*

Participants shared that at times they discuss the challenges they face with family members in an attempt to find solutions or to express their frustrations. The CCGs’ inability to separate from their client’s problems may be an indication of insufficient coping skills. It appears that the strategies they are using to cope are not effective.

4.8.4.2  **Anxiety about their safety**

There is also the issue of not feeling safe in the communities the CCGs reside in because they become the enemy of many of their neighbours.

*P: “You come back to sleep at your house when you got the neighbor arrested.” FG1*

This participant shared that she feels unsafe and is constantly nervous that her neighbours may attack her and her children. The CCGs feel vulnerable and exposed, and are of the opinion that their reward is far too small considering the risks they take.
4.8.4.3 Losing sleep because of difficult cases
The participants reported that their work causes stress and that they lose sleep thinking about their clients and the challenges that they encounter.

P: “I do not even sleep at night” FG2

While their work can be fulfilling when CCGs are successful in helping their clients, many cases remain unresolved and hence they feel stressed.

P: “It’s stress only.” FG1

P: “Confusion” FG3

P: “We do not sleep because of these cases we are exposed to, they are really hard. They make us sick, rape nje, a rape case, having to go and testify in court. It affects you badly.” FG1

Rape cases were reported to be the hardest to deal with and the situation is made worse by the fact that CCGs are the ones to report them or to testify in court.

4.9 Support and coping strategies used by CCGs
4.9.1 Support available to CCGs
The issue of support appeared to evoke feelings of disappointment in the caregivers. They felt that the nature of their work leaves them vulnerable to many things and that not much was done to support them.

P: “Like we were saying, that if only there was a place where we could offload, you see express everything that you are feeling inside.” FG3

Participants said that they would like debriefing sessions as they currently feel unsupported and are left to cope on their own.

P: “There is no support, we see for ourselves how we cope” FG1

P: “We have a supervisor who is also lazy, who is a nobody like us.” FG1
The CCGs report to supervisors who are expected to assist with difficult cases. However, it appears that many supervisors do not perform this role. There does not seem to be a good relationship between some CCGs and their supervisors. The majority of the participants agreed that they received no support at all.

A few caregivers said that there are systems in place to ensure that they are coping and are receiving the support they need.

P: “We have workers support groups where we come together to share the challenges we come across eeh.... We have peer support groups where we come together, where we give each other encouragement. Normally on Fridays we have spiritual sermons, where we come together and pray.” FG2

Nonetheless, it would appear that the above case is an exception.

4.9.2 Coping strategies employed by CCGs

4.9.2.1 The need for financial gains that reflect the risks

The participants come from backgrounds that are similar to those of their clients in terms of financial instability. They reported that they are not coping financially and are not gaining many benefits as CCGs.

P: “We would like a higher salary.” FG1

The participants felt that the effort they put into their work is not rewarded appropriately. They noted that they receive no benefits and that the stipend is insufficient.

4.9.2.2 Interpersonal relations that assist with coping

The participants reported that they rely on their interpersonal relationships to help them cope with the nature of their work.

P: “When we arrive at home after dealing with our work, we get to exercise, to talk with our family, talk to them about your day, and listen to others. Others tend their gardens.” FG2

P: “We talk with each other and seek advice from each other.” FG1
It appears that conversing with each other and sharing the difficulties of their work is one strategy which CCGs found most helpful.

4.9.2.3 *Intrapersonal coping*

CCGs reported giving more than what is required of them. They give of their time, money and resources to assist their clients. They reported that giving all that they can results in feelings of altruism and reinforces the value of CCGs in their communities.

*P: “This 1.5 that we are earning that is little, we have to use it to pay for people’s transport fees.”* FG1

Using the little money they have to help where they can is a challenge for CCGs, but it is also a way of coping; knowing that they did all they could, gives them a sense of achievement.

4.9.2.4 *The need for psychological support*

The participants reported that they are not receiving any psychological support to help them cope with their effects of their work. They stated that they would like debriefing sessions and counseling sessions.

*P: “We too need counseling, go to that door”* FG1

Across all focus groups participants said that counseling sessions would help them cope. They added that it would be of great benefit if their supervisors could conduct debriefing sessions.

However, they reported that they are taught self-care strategies which include using available resources to de-stress. These include tending the garden, exercise, reading, and many other strategies which caregivers find calming and enjoyable.

*P: “Others go into the garden….maybe look at your spinach there…then go into the house and sit with your family.”* FG2

This participant shared some of the self-care strategies CCGs use which they find helpful, including spending time with family, gardening, and exercising.
4.10 Summary
The study’s findings show that CCGs carry out multiple tasks in the communities within which they work. These include profiling and referring clients to various departments such as Home Affairs, SASSA, and Social Development; providing care and support for people living with HIV; addressing the needs of vulnerable children and families; educating family members; testifying in court; and administrative duties. However, CCGs not only perform the tasks identified by their scope of practice, but go further. They give of their time, money, and energy to ensure that their clients are assisted. They sacrifice their sleep and off duty time to assist clients.

The participants stated that they feel competent in their work because they are adequately trained. The skills imparted to them through workshops and weekly classes have enhanced their knowledge and skills. However, they encounter numerous challenges that they attribute to the lack of collaboration between CCGs and the departments to which they refer their clients. The CCGs reported that their clients do not always receive the assistance they require, with some waiting years without any progress. This makes CCGs appear incompetent and of no value to the community and hence it becomes more difficult for them to carry out their work because community members become aggressive or refuse to let CCGs into their homes.

Community caregivers are funded by government but are not employed by the government and hence are not recognised as government employees. They feel devalued because they work with great commitment but receive meager rewards. They endure harsh working conditions, are not provided with adequate resources to perform their duties, and their lives are continuously at risk because of duties such as reporting and testifying.

The challenges CCGs encounter affect them financially, interpersonally, intrapersonally, and psychologically. Participants reported that they do not receive sufficient support to cope with the nature of the work they carry out.
Chapter five

5 Discussion

5.1 Introduction

This chapter discusses the results of this study from the perspective of previous research. The previous chapter identified and analysed the themes in relation to the role of CCGs, the experiences and challenges they face, the effect of caregiving work on CCGs, and the coping mechanisms they adopt. This chapter discusses these themes within the framework of the research questions.

5.2 Role of CCGs

In South Africa, community caregiving work is viewed as a nurturing task and hence is mostly done by women (Daniels et al., 2012). Those who volunteer as community workers come from similar backgrounds to those of their clients. Community care workers are usually women who are unemployed, have no professional training, and come from underprivileged socioeconomic backgrounds (Akintola, 2006). The participants in this study were mostly women who reported that they come from poor socioeconomic backgrounds and were motivated to become CCGs because this would enable them to both assist people in their communities and provide them with skills which could lead to better employment. These motivations are similar to the reasons for volunteering identified by Akintola (2011) which include humanitarian obligation, skill recognition, and career benefits. The main reasons the participants in this study stated for becoming a CCG were that it gave them something to do, that volunteering and later becoming a CCG would improve their chances of finding a job, that it provides an income, and that it is a way to care for people in need.

The SDT assists in conceptualising how work impacts on psychological well-being. Employees that have an energetic, optimistic, and effective approach to their work are likely to feel a sense of fulfillment and well-being (Bakker, Schaufeli, Leiter & Taris, 2008). People who find their work fulfilling will be more dedicated and vigorous. Strong identification with one’s work gives one a sense of enthusiasm, significance, and pride in the work and hence leads to good
psychological health. The SDT highlights that the reason for choosing a certain career/job can determine if that job will be fulfilling and hence enhance psychological well-being or if it will be frustrating. It states that intrinsically motivated people chose a particular career or job because they enjoy it and hence engage with it optimally (van Breek et al., 2011). This has a positive impact on their well-being and boosts psychological health. On the other hand, extrinsically motivated people choose certain careers/jobs because of their instrumental value (van Breek et al., 2011). The outcome (such as income and the opportunity for growth) motivates them to do their work. Such persons are likely to find their work frustrating.

In terms of CCGs’ motivations to do their work, the study’s results indicate that these motivations are mainly extrinsic. They volunteered to become CCGs because they saw it as a way of improving their financial circumstances, and as a stepping stone to better employment. Becoming a CCG would improve their chances of receiving a learnership and training for a better job.

On the other hand, the intrinsic motivations include finding fulfillment through helping others and enjoying their work in the community. However, becoming a CCG is regarded as a stepping stone to being a social worker or a nurse, which they regard as work that would yield ultimate fulfillment. The CCGs’ extrinsic motivations carry more weight and hence, according to the SDT, their work could easily lead to feelings of frustration.

Community caregivers are a less costly approach to delivering certain services to communities (Mwai, Mburu, Torpeg, Frost, Ford & Seeley, 2013). The services delivered by CCGs are similar yet vary slightly from context to context. In areas riddled with malaria and pneumonia, CCGs assess, classify, and treat people with these illnesses (Mwai et al., 2013). In contexts with a heavy burden of HIV/AIDS, the key role of CCGs is to provide HIV counseling and testing, ART related support (Schneider & Lehmann, 2010), and home-based care activities (Zachariah et al., 2006). Community caregivers also provide services such as ante- and postnatal care, promotion of breastfeeding and immunization, advising clients on family planning, and formulating birth plans (Mwai et al., 2013). They offer health education and carry out the important role of assessing their clients’ needs and advising them of the services available (Uys, 2002).
The burden of epidemics such as HIV/AIDS rekindled enthusiasm for CCGs (Shneider et al., 2008). Community caregivers were initially mainly lay health workers who attend to the health needs of communities (Friedman, 2005). In South Africa in particular, the community level approach was adopted to alleviate the strain on the health system; thereafter, other departments were encouraged to develop their own community care programmes (Friedman, 2005). The growing need to address the plight of orphaned and vulnerable children led the DSD to develop its own category of CCGs (Schneider et al., 2008). According to the Department, the services that CCGs provide include:

- Care, counseling and support to people living with HIV/AIDS.
- Addressing the needs of child-headed households.
- Linking families and caregivers with programmes that address poverty.
- Providing food parcels and food supplements.
- Providing information to improve access to social, educational, housing, material and healthcare services.

These functions overlap with the roles that the participants reporting carrying out in their communities. They identified the following functions:

- Providing care and support to people living with HIV
- Addressing the needs of vulnerable children and families
- Linking families with programmes that address poverty
- Educating family members

The CCGs that took part in this study said that they felt that they adequately carried out their roles in their communities and that they were more than sufficiently trained.

5.3 Training of CCGs

The training of CCGs is different from programme to programme. The CCGs that participated in Uys’ (2002) study were trained for three months before being appointed, while the volunteers that took part in Akintola’s (2011) study received six weeks training in theory. According to Schneider et al. (2008), the recruitment process for CCGs included calling for volunteers who
had been doing volunteer work in the community through community-based organisations. The participants in the current study reported varying levels of experience and exposure. Some are qualified auxiliary nurses and auxiliary social workers. They all have matric and all started off as volunteers prior to being appointed as CCGs. They receive continuous skills development workshops and are part of a programme that enhances their skills in work with vulnerable children and youth. According to the participants, this training has equipped them to fulfill their roles in their communities. Hermann et al (2009) note that adequate training is one of the factors that determine a programme’s success.

5.4 Challenges encountered by CCGs
It is difficult to quantify the contribution made by CCGs because there are blurred boundaries between the various roles of caregivers (Schneider & Lehmann, 2010). In 2001, South Africa experienced a rapid growth of NGOs which employ CCGs in the health and welfare sectors (Schneider & Lehmann, 2010). These NGOs gave various titles to caregivers that performed different functions in communities (Schneider & Lehmann, 2010). Training also varied according to the service provided. Titles such as child care workers, VCT counselors, ART adherence counselors, DOT supporters, and home-based carers were introduced during this period (Schneider & Lehmann, 2010). A more general category of caregivers was developed in 2007 where the care worker had received training in more than one of the above-mentioned categories. The role of the caregiver is thus determined by the training they have received or their qualifications, as well as the sector in which they work.

5.4.1 Inconsistency of CCGs’ roles within the community
The CCGs that took part in this study are funded by the welfare sector, and they thus focus on addressing welfare needs. The participants reported that one of the challenges they face is that community members do not understand their role, and expect them to take care of every household need. Community members can make outrageous demands on CCGs and threaten to report the caregiver if they do not meet such demands (Akintola, 2008). An example would be when family members expect the caregiver to visit their home daily to look after their ill family member. The role of the caregiver is to educate the family on how to look after the ill person
(Wringe et al., 2010), but family members expect the caregiver to physically care for their sick relative on a daily basis (Akintola, 2008).

5.4.2 Ill-informed perceptions of CCGs
On the opposite end of expecting caregivers to visit on a daily basis are family members who will not accept any assistance from CCGs. As noted earlier, CCGs perform a variety of tasks. However, there is a tendency for community members to perceive CCGs as people employed to work with people living with HIV. This comes as no surprise as the rekindling of enthusiasm for CCGs was brought about by epidemics such as HIV/AIDS (Coovadia et al., 2009). HIV/AIDS is one of the most highly stigmatised medical conditions, especially in sub-Saharan Africa (Singh, Chandoir, Escobar & Kalichman, 2011). By virtue of the fact the CCGs also work with PLWA, they become targets of discrimination and prejudice (Singh et al., 2011). Some families deny CCGS access to their homes because they fear that constant visits by a caregiver will make it easy for their neighbours to pinpoint that they have a family member who is HIV positive, rendering them vulnerable to stigmatisation. Families with members suffering from illnesses other than HIV/AIDS also deny caregivers access because they fear being stigmatised. The fact that caregivers were previously assigned to ensure a peaceful death by persons that the health system could offer no hope to (Claxton-Oldfield & Claxton-Oldfield, 2007) is another reason why community members are reluctant to accept help; a visit from a CCG may imply that there is no hope for their ill family member. Thus, CCGs find themselves having to persuade community members to accept help because they cannot neglect those in need.

5.4.3 Lack of a collaborative working relationship
The participants noted that another reason why they are denied access by community members is because CCGS are viewed as untrustworthy. The study’s results show that many of the challenges confronting CCGs stem from a lack of integration and collaborative working relationships. Collaboration between all stakeholders is vital for the success of a CCG programme (Celletti, Wright, Palen, Frehywot, Markus, Greenburg, de Aguiarc, Camposd & Samb, 2010). A well-functioning service delivery programme depends on the involvement and commitment of all key players.

Sips, Mazanderani, Schneider, Greeff, Barten & Moshabela (2014) concur that collaborative working relationships are vital and add that the success of a CCG programme is dependent on
many factors, including well-functioning referral systems, adequate supervision and monitoring of CCGs, integration between systems, and collaborative planning. Sips et al (2014) also note that it is crucial that CCGs’ skills and contributions are recognised.

A lack of integration and collaborative working relationships is a problem for some CCG programmes (Schneider et al., 2008). The current study found that the lack of collaborative working relationships between CCGs and the organisations and departments they refer to poses a massive challenge. The study participants reported that many of their referrals are not attended to by the various departments. This puts them in a position where they are continuously visiting homes and initiating a process which does not yield results. Community members get frustrated with the caregivers when their needs are not met, making life uncomfortable for CCGs in their communities. The lack of positive results from CCG interventions leads to community members denying them access to their homes. In some cases, CCGs end up hiding from their clients who still have not received any response from the departments. In turn, CCGs have resentful feelings towards government employees and blame them for the lack of progress (Schneider et al., 2008). The study participants noted that some government employees do not attend war room meetings, do not appreciate the value and contribution of CCGs, and do not treat referrals by CCGs with any sense of urgency.

The SDT suggests that self-motivation is sourced from three basic psychological needs, namely, competence, relatedness, and autonomy. The need for competence is concerned with the psychological need to be self-assured about one’s capability of impacting on outcomes (Ryan & Deci, 2005). Competence relates to feelings of effectiveness when engaging with one’s environment (Albrecht, 2015). When a person feels that they have the capacity to affect or to bring about change in their environment, their need for competence is fulfilled.

5.4.3.1 CCGs’ contributions are undermined
Schneider et al (2009) also found that the high levels of dissatisfaction among caregivers stemmed from their perceptions that their input was not recognised by departmental authorities and communities. Regardless of their skills, their contribution was devalued (Schneider et al., 2009). The CCGs find themselves in situations where their knowledge is questioned and their advice is second guessed because they are not perceived as someone with status or knowledge. They stated that some government employees regard them as a nuisance, and treat them harshly.
They humble themselves and put up with such treatment in order to ensure their work is done because they live in the same communities as their clients.

P: “Like when we go to their offices, they have that thing of gossiping about us saying ‘eish here they come these people’. We are not taken seriously. Even when you want to make copies you have to beg and beg.” FG3

Resentment towards some government employees is exacerbated by CCGs’ perceptions that these employees enjoy good working conditions, while CCGs work under harsh conditions.

5.4.4 Unfavorable environmental conditions
The harsh environments that CCGs work in are very distressing (Demmer, 2007). On average, each caregiver is expected to visit at least three homes a day. They walk through the bush in unsafe areas, under bad weather conditions and to top it all have to deal with hostile clients (Demmer, 2007).

5.4.5 Going beyond their scope of practice
The CCGs also feel that they do more than they should for their clients. They make personal sacrifices such as sharing their resources (Cataldo, Kielmann, Kielmann, Mburu & Musheke, 2015) and using their own money (Daniels et al., 2012) to assist their clients. The findings of this study indicate that, like their clients, CCGs come from unfavourable socioeconomic backgrounds, but they make sacrifices to assist their clients. In sacrificing their resources, caregivers gain a sense of accomplishment in advocating for their clients (Cataldo et al., 2015). This could be a way of increasing their self-esteem or their in-group membership status. According to the social identity theory, part of a person’s self-concept is defined by belonging to social groups (Trepte, 2006). Social identity involves membership of a certain group and the value of that membership (Trepte, 2006). To enhance self-esteem and to develop a positive social identity, people behave in ways that elicit a positive response from their social groups (Trepte, 2006).

5.5 Effects of community caregiving work
Community caregiving work has an effect on numerous areas of the caregiver’s life. These include financial constraints (Daniels et al., 2012; van Zyl, 2011), and interpersonal (Mwai et al.,
5.5.1 Financial impact
The results of this study indicate that CCGs often find themselves in situations where they use their own money to assist clients. This results in further financial constraints on CCGs because they come from similar socioeconomic backgrounds to those of their clients. Caregivers feel the pressure to financially assist the families their work with, especially if they are providing care to the breadwinner who may be unable to work because they are ill (Ama & Deloilwe, 2011). Caregivers use their own money to carry out their duties because they are provided with inadequate resources. They pay taxi fares for themselves and their clients to travel to various organisations or departments to seek help for their clients (van Zyl, 2011). They are so keen to make a difference in their communities that they are prepared to use their own resources to do so.

The relative deprivation theory holds that subjective interpretations made by people about their lot in life should be examined when looking to predict their responses to inequality (Osborne & Sibley, 2013). When an individual feels relatively deprived compared to other individuals, they are likely to respond with a level of stress or other mental health reactions (Osborne & Sibley, 2013). When an in-group feels relatively deprived compared to other groups they are likely to respond by advocating for social change and acting collectively against the deprivation (Osborne & Sibley, 2013). The CCGs are an in-group who feel relatively deprived compared to other groups; they come from societies that are deprived, and hence their response is to collectively act in support of change. They use their own resources to support social change, the change in this case being assisting their clients to access the support structures required to address their problems.

5.5.2 Interpersonal effects
The CCGs reported that their efforts to assist their clients do not always yield results, negatively affecting their relationship with their clients and with government employees. Thus, the psychological need for relatedness is not met. This basic need is concerned with being connected with and supported by others (Ryan & Deci, 2005) that require a satisfying and understanding relationship with those around one. In the workplace this need would be fulfilled by a supportive, understanding, and respectful relationship with clients, colleagues and superiors. This is similar
to the support dimension of the DCS model where support and integration from colleagues and superiors are considered. In terms of the themes extracted from the data, the CCGs’ relationships with their clients and colleagues are presented below.

The CCGs’ failure to obtain positive results from their interventions is attributed to a poorly functioning referral system (Celleti et al., 2010). Caregivers work in the communities in which they reside. Their clients are their neighbours with whom they have a comforting and caring relationship; hence, caregivers are integrated with the families they assist. They consult each other for advice and share resources (Cataldo et al., 2015). Some clients become close to their caregivers because they are able to open up to them more easily than they can with their families (Cataldo et al., 2015). When caregiver interventions do not yield results and families refuse to let them in their homes, their interpersonal relationships with neighbours are affected. CCGs are also stigmatised because they work with people living with HIV/AIDS (Singh et al., 2011); like their clients, they are isolated due to such stigmatisation (Mwai et al., 2013).

5.5.3 Psychological effects
According to Akintola (2008), the work that the caregivers perform often results in a lot of stress. Stress refers to the emotional or mental strain which results from adverse situations. Other symptoms that result from community caregiving include burnout (Demmer, 2007), and socio-economic and emotional stress (Daniels et al., 2012). This study produced similar results. Furthermore, the caregivers added that they feel anxious and often experience episodes of insomnia. They reported that they adopt their clients’ problems and when these problems are not resolved they become so preoccupied with them that it affects their sleep.

The CCGs stated that their work is highly stressful. Akintola (2008) notes that this is because they have to deal with hostile community members, family members who are in denial, harsh working environments, and the physical condition of the patients they attend to. Schneider et al. (2009) add that the lack of integration and support, and conflict between caregivers and health professionals also has negative impacts on the caregiver. The results of this study concur with the findings of previous studies. In addition, the participants reported that they live in fear in their communities. Their duties include reporting crimes, abuse, and neglect in their communities; this
put them in a situation where they may become enemies of their neighbours who they have reported to the police. As noted by Thabethe (2011), CCGs are themselves economically unstable, and provide care to people in similar circumstances. Even though their work comes with heightened risks, they do it because their stipend assists them financially.

5.6 Support available to CCGs and coping skills employed by CCGs

According to the DCS model, environmental stimuli influence emotional reactions and behaviour (Siegriest, 2010). It notes the need to balance the workload, control, and support in order to reduce strain on the jobholder. The ERI model emphasises the need for adequate rewards in order to reduce strain. Community workers face difficult and ambiguous working conditions (Daniels et al., 2012). In terms of these models, difficult working conditions should be met with accurate rewards.

Below is an illustration of the support that CCGs are currently receiving versus the support they would like to be available in order to better cope with their work.

Diagram 5.1

<table>
<thead>
<tr>
<th>Support currently provided</th>
<th>Support desired</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Self-care lessons</td>
<td>• Support groups</td>
</tr>
<tr>
<td>• War rooms (not functioning well)</td>
<td>• Debriefing sessions</td>
</tr>
<tr>
<td>• Supervisors for support</td>
<td>• Counseling when needed</td>
</tr>
<tr>
<td>• Leave</td>
<td>• Stationary</td>
</tr>
<tr>
<td>• Support groups (functioning for a few)</td>
<td>• Well attended and functioning war rooms</td>
</tr>
<tr>
<td>• Recognition by government departments (e.g., not having to queue)</td>
<td>• Rewards</td>
</tr>
</tbody>
</table>
According to the caregivers, there is a huge discrepancy between the support that is available and that which is needed. Schneider (2008) states that community caregivers are assigned a professional nurse who supervises and supports them. The caregivers in this study reported that they are supervised by another caregiver who has more experience in the field and is paid a stipend that is R500 more than theirs. The role of the supervisor is to ensure that the caregivers perform their duties and to assist them when they encounter difficulties that overwhelm them (Friedman, 2007). Supervisors participated in the second focus group. They stated that they run debriefing sessions, support groups, and worship sessions as means to ensure the well-being of caregivers. However, the caregivers said that this was not the case in most of the wards where they worked. Thabethe (2011) found that many caregivers reported doing nothing about their stress and letting it work itself out.

The caregivers are given annual leave, which Claxton-Oldfield and Claxton-Oldfield (2007) found to be of assistance because it allows time off work. Leave means time away from stress causing situations, and time to regroup. Another support strategy available to the caregivers is training in self-care. They are taught various methods to reduce the tension brought about by their work. The self-care methods reported by CCGs included offloading on each other, spending time with their families, tending their gardens, listening to music, and going to church. They reported that these activities take their minds off work, with positive effects.

However, the participants stated that the support available to them is insufficient and they would like to see more support structures in place. They identified the need for a salary increase, stationary for work purposes, counseling and interventions to address their relationship with government employees so that they are taken more seriously.
Chapter six

6 Conclusion

6.1 Background and Motivation
The numerous epidemics that burden African countries have caused a crisis in their health sectors (Callaghan, Ford & Schneider, 2010). South Africa is one such country that lacks sufficient resources to adequately deal with the health issues it faces (Bennet, 2004). In response to the shortage of healthcare professionals (Schneider, Hlophe & van Rensburg, 2008), South Africa has allocated more resources to growing the number of lay workers, including home-based care workers, lay counselors, and DOT supporters (Schneider et al., 2008). The DSD has also created a category of CCGs that focus on addressing the needs of vulnerable and orphaned children (Schneider et al., 2008).

The current literature on the experiences of CCGs suggests that caregivers face realities that leave them vulnerable (Thabethe, 2011). There is a paucity of research on CCGs in South Africa and the studies that have been conducted have not focused on the psychological coping mechanisms adopted by CCGs (Akintola, 2008). The primary focus of this study was to explore the perceived impact of the CCG’s work experience on their psychological wellbeing.

6.2 Research questions
- What is the role of the community caregivers on the DSD pay roll?
- What challenges do CCGs encounter in their work?
- What is the perceived impact of the CCG’s work experience on their psychological health?
- What support systems and coping strategies do CCGs use to cope with the demands of their work environment?

6.3 Summary of findings and conclusions about the research questions
The roles that the CCGs reported carrying out include providing care and support to people living with HIV, addressing the needs of vulnerable children and families, linking families with
programmes that address poverty, and educating family members. They added that they are confident in carrying out these roles because they have been sufficiently trained.

The study found that many of the challenges that CCGs experience stem from a lack of integration and collaborative working relationships. This seems to be a common problem among CCG programmes (Schneider et al., 2008). The CCGs expressed feelings of being undermined and devalued by government employees. The lack of positive outcomes from CCG interventions leads to community members lacking trust in CCGs and questioning their value to the community. Lack of recognition by government employees and communities leads to high levels of dissatisfaction among caregivers (Schneider et al., 2009). Efforts have been made to promote a good working relationship between caregivers and other departmental employees. These include war rooms where they meet with the departments they refer to and obtain assistance with their cases. However, the participants reported that the war rooms are currently not serving the purpose they were intended for because many of the departments do not attend.

The CCGs also experience frustration as a result of their encounters with community members as well as other professionals (Schneider et al., 2009). The perceived impact of caregiving work leads to CCGs feeling exploited, distressed, devalued and stressed. Demmer (2007) reiterates these findings and notes that community caregiving work can result in stress and burnout for the caregiver, while Daniels et al (2012) add that community caregiving work can result in emotional and socioeconomic strain. The CCGs felt that there is a need for the work that they do, and that it could lead to a significant improvement in the lives of many community members. They play an important role in meeting the health and social welfare needs of the majority in South Africa (Clarke, Dick & Lewin, 2008). However, devaluation of their work and undermining of their skills hinder progress.

In an effort to reduce programme costs and makes optimal use of available resources, more experienced CCGs are trained to supervise CCGs and offer guidance and support (Schenk, Michaelis, Sapiano, Brown & Weiss, 2010). While some CCGs reported that this form of supervision is working well, others stated that they receive no support. It was noted that the supervisors themselves have no recognisable status, and are also looked down upon. The
methods that were reported to be working are the workshops run for CCGs as well as the self-care methods that they are taught as both improve their self-esteem and knowledge. Issues that were identified as requiring urgent intervention are the safety of caregivers that causes much distress, as well as ensuring that referral institutions carry out their tasks because this contributed to community members regarding CCGs as inadequate.

The CCGs highlighted that there is a huge discrepancy between the support that is available and that which is needed. The study found that CCGs lack sufficient coping skills to deal with the demands of some aspects of their work.

6.4 Unique contribution of the study
This study expands our understanding of the needs and coping strategies of CCGs at the local level. It explored CCGs’ experiences and the psychological impact of their work. It also explored the strategies used by CCGs to cope with their work. The study thus assists in identifying CCG best practices and identifies the factors that have a negative impact on CCGs’ service delivery.

6.5 Implications for policy
While policies have been adopted, there are still blurred boundaries with regard to the roles and expectations of the various types of community workers (Schneider & Lehmann, 2010). One of the main stressors that CCGs have to deal with is uncertainty about whether they should be regarded as volunteers of full members of the healthcare system (Daniels et al., 2012). Community members are not sure who CCGs are answerable to (Daniels et al, 2012). This uncertainty has led to poorly understood and regulated policies for CCGs (Daniels et al., 2012), which renders them vulnerable to exploitation.

6.5.1 Implications for CCG support
Community caregivers face ambiguous and difficult working conditions (Daniels et al., 2012) that lead to heightened anxiety and stress. Some caregivers reported that they do nothing; over time the stress goes away (Thabethe, 2011). This could be an indication that they lack coping skills or do not having the resources required to reduce stress. This suggests that more support needs to be provided to CCGs to help them cope.
6.5.2 Implications for practice
As noted earlier, there is limited research on CCGs in South Africa and the studies that have been conducted do not focus on psychological coping among caregivers (Akintola, 2008). The findings suggest that the experiences of CCGs funded by different departments may vary; hence, a ‘one-size-fits-all’ approach to designing CCG programmes will not be effective because context plays a significant role CCGs’ experiences (Wringe et al., 2010). It is important to understand the experiences of careworkers in particular contexts which will lead to the design of effective programmes with appropriate resources and support systems (Wringe et al., 2010). This study focused on DSD CCGs, who are part of a certificate programme run by the REPSSI. The findings from the three districts indicate some generalizability across CCGs as their experiences were similar. They experience similar challenges in their work, use similar coping strategies, and are affected by their work in similar ways. However, there is a limitation in terms of generalizability because during the data collection phase, the CCGs kept comparing their experiences to those of CCGs from other programmes, suggesting a discrepancy in experiences across programmes. More research is thus needed on CCGs in the South African context.

6.5.3 Implications for theory
Community caregivers feel positive about the contributions they have the potential to make in their communities provided that they received the support they require. The complexity of the problems that they encounter makes it difficult for them to cope (Uys, 2002). The CCGs regard the training they receive as more than sufficient. However, while they feel competent in their work, they expressed the need for more recognition and authority.

6.6 Limitations
Some of the limitations of this study are related to the sample. The sample consisted of CCGs employed by the REPSSI, who are on the DSD payroll. Thus, the sample consisted of paid CCGs that are receiving constant mentoring and training, and that work under the DSD. Their experiences could differ from those that volunteer and do not receive a stipend, do not receive continuous training to enhance their knowledge or are employed by a different department. Some programmes offer benefits such as the provision of foodstuffs, end of year gift vouchers, umbrellas, shoes, uniforms and sponsorship of children’s school fees, and sanitary products (Akintola, 2011). The efforts-rewards-imbalance could be perceived differently from programme to programme.
Furthermore, in the focus group that included supervisors, the CCGs were noticeably quiet, and would look to the supervisors for a response. The presence of supervisors could have limited the openness and honesty of the CCGs in this group. Few stated their disagreement with supervisors, and many remained quiet.

There could also be limitations in terms of the transferability of the study’s results. The study sampled CCGs under one department and one certificate programme. It is likely that CCGs under different programmes would have different experiences of the treatment they receive from their department and the clients they work with. Studies conducted by Schneider (2008) and Thabethe (2011) affirm the findings of this study. Schneider (2008) also found that CCGs’ dissatisfaction was the result of being undermined, not being given recognition, and their sour relationship with professionals. Thabethe (2011) found that caregiving can cause further financial constraints and that caregivers lacked sufficient coping skills. The results of this study concur with these findings. Sampling a wider range of CCGs would allow for comparison, and strengthen transferability.

The questions asked in the focus groups appeared to be clearly understood, and participants responded appropriately. The researcher was also very conscious of not asking leading questions. The groups were run using the participants’ mother tongue, facilitating interaction.

6.7 Recommendations based on the findings
The study’s findings indicate that the main gaps in providing adequate support for the healthy psychological functioning of CCGs in their work include: collaborative working relationships between CCGs and government employees, well-functioning referral systems, recognition of CCGs, increased rewards, and psychological support. Based on these gaps, the following recommendations are made:

6.7.1 Promoting collaborative working
Community caregivers and government employees need to work collaboratively to ensure proper service delivery to communities. The CCGs feel undermined and taken for granted; the relatedness need identified in the SDT is not met. The CCGs do not feel accepted by and connected to government employees. Instead, they feel devalued and undermined. Celletti et al., (2010) state that collaborative working relationships between all stakeholders are vital for the
success of a programme. A system that will improve communication and facilitate interventions needs to be put in place.

6.7.2 Addressing referrals
The CCGs reported that their referrals sometimes go unattended to for years. This makes life uncomfortable for caregivers in their communities because they feel pressured to hide from clients and have to deal with the hostility of new clients who have heard that their interventions are ineffective. Well-organised and well-functioning referral systems are important for the success of a programme (Sips et al., 2014). While war rooms have been put in place to facilitate inter-organisational referrals and to enable CCGs to receive assistance with their cases, it was reported that they are not functioning well due to poor attendance by the various departments. Measures need to be put in place to ensure attendance at war rooms.

6.7.3 Recognition of CCGs
The CCGs reported that they lack recognition and their role is not acknowledged. When they accompany clients to Home Affairs or SASSA, they have to stand in queues and sometimes leave at the end of the day having not received the help that their client requires. The caregivers reported that they have to visit at least 60 homes a month and standing in queues with a client means that they fall behind in their work. They also reported having to wake up at 3am to ensure that they are at the front of the queue; this cuts into their private time. The CCGs feel that they should not have to stand in queues because they also serve the community. Their role in communities is vital because they understand the history of their communities and are able to communicate with their clients without using jargon (Pinto, da Silva & Soriano, 2012). Recognising the importance of the role that CCGs play and integrating them into social services and the health system could yield positive change in communities (Neuhausen, Grumbach, Bazemore & Phillips, 2012).

6.7.4 Increase rewards
The caregivers view the R1 600 stipend as far too little compared with the effort they put into their work and the risks they take. Jehanzeb, Mazen, Anwar and Aamir (2012) found a positive correlation between rewards and job motivation which in turn has a positive impact on job satisfaction. The CCGs noted that, not only is their stipend small, they also assist their clients financially. They suggested that they should be provided with all the necessary resources to do their work as well as petty cash to assist clients with transport costs.
The participants also reported that they feel that there are no career growth opportunities for CCGs who are part of the certificate programme run by the REPSSI. They would like to be offered learnerships to study further and grow their careers. Zhou, Zhang and Montoro-Sa´nchez (2011) note that extrinsic rewards, which are tangible rewards such as a salary increase and bonuses, and intrinsic rewards such as work flexibility and extensive learning opportunities are both necessary to increase motivation. Intrinsic rewards are seen as having a more positive impact on employee behaviour. Providing the CCGs with opportunities to study further could have a significantly positive impact on their intrinsic motivation.

6.7.5 Psychological support
The CCGs reported that the work they do in the community affects them negatively and that they do not receive sufficient support. While they are taught self-care methods, these do not always work due to the severity of their distress. They felt that debriefing sessions and counseling services would help them to cope better. Offering counseling to employees is an indication that the organisation cares about its employees (Torun, 2013). It reduces absenteeism, complaints, and dismissals (Mapira et al., 2013). Counseling thus has a positive impact on employee well-being.

6.8 Conclusion
This study employed the SDT and ERI model to examine the impact of community caregiving work on caregivers. The SDT posits that the tasks that individuals tackle are driven by a variety of reasons, and that, in turn, these reasons influence their behaviour and well-being (Chambel et al., 2015). It differentiates between intrinsically and extrinsically motivated individuals, with the former leading to optimal functioning because the tasks are engaged in with desire, while the latter functions have instrumental value (van Breek et al., 2011). This theory is applied to understand how work engagement influences an individual’s psychological well-being. A workplace that satisfies the need for competence, relatedness, and autonomy promotes good psychological health (Deci & Ryan, 2008).

The research questions and the data collected from the CCGs assisted in gaining an understanding of whether the basic psychological needs posed by the SDT are promoted by CCGs’ work environment. In turn, this enabled the researcher to determine whether or not this work environment promotes good psychological health or has an adverse impact on CCGs’
psychological well-being. The study’s findings validate the SDT as they indicate that CCGs are mainly extrinsically motivated and regard community caregiving work as a means to earn an income and access opportunities for better employment; hence they are more likely to be dissatisfied with their work. The findings also indicate that the psychological well-being of the CCGs is negatively impacted by their work because their basic psychological needs are not all met by their work environment.

The study found that CCGs feel that they have a sense of choice and control in their work and that they feel competent and function well. However, the results suggest that the relatedness need is neglected in the field of community caregiving. The CCGs noted that the lack of a good working relationship with government employees, colleagues, and community members causes much frustration. The lack of relatedness affects their freedom and competence levels because it leaves them feeling powerless and undermined.

The ERI model also assisted in understanding the relationship between the workplace and individual well-being. Social reciprocity is the core of this model (Siegriest, 2010). This implies that certain obligations and tasks are performed in exchange for adequate rewards, which include money, career growth, and increased self-worth (Siegriest, 2010). The effort that employees expend in their work is reciprocated by reasonable rewards from their employers. According to this model, stress and associated negative feelings towards work are a result of failed reciprocity.

The CCGs who participated in this study felt that the effort they put into their work is not adequately rewarded. They reported that they experienced many challenges which far outweigh the benefits and support provided to them. The study found that the challenges experienced by CCGs include delayed or no attention being paid to their referrals, being undermined by government employees and community members, and enduring harsh environmental conditions in carrying out their work. They also reported that they lack all the resources required to carry out their work, risk their own safety by reporting crimes in their communities, and are stigmatised because they are perceived as AIDS workers. They added that although they are adequately and continuously trained, they felt that they lack career development opportunities, are restricted in terms of making interventions and that they are not given a platform to practice the theory they are taught. In the face of such challenges, they lack sufficient support and feel exploited because their perception is that they are being used by NGOs to solicit funding. Since
the CCGs reported that they are not properly rewarded for their efforts, in terms of the ERI model, there is failed reciprocity.

Previous studies have identified stress, burnout (Demmer, 2007), and emotional and socioeconomic strain (Daniels et al., 2012) as negative impacts of community caregiving work. The findings of this study concur with previous research. Some caregivers reported that they do nothing about the stress they experience as a result of their work; instead, they leave it to work itself out. This is indicative of poor coping. There is a need for stakeholders to address the negative effects that caregiving work has on CCGs. The participants suggested that stakeholders need to ensure that they are provided with all the resources they need for their work, that counseling be made available, that the war rooms function properly, career growth opportunities are made available, and that their importance and significance is recognised so that they do not have to wait in queues with their clients at various government departments and institutions.
7 REFERENCES


treatment outcomes in a resource-limited rural district in Malawi. *Royal Society of Tropical Medicine and Hygiene, 101*(1), 79-84.

Appendices

Appendix 1
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Generic schedule
Focus group schedule

Opening
The researcher will introduce herself. She then will briefly talk about the study, and ask if there is anything the participants would like clarification on. She then will highlight the issue of confidentiality and will encourage the participants to express themselves freely and truthfully.

The researcher will then inform the participants about the focus group process and what is expected of them as participants in the study.

The following are questions that will be covered in the focus groups. The participants will be allowed to verbally express their views as well as write down on answer cards their responses to the questions, and at the end of the focus group discussion the participants will then organize the cards into themes.

Background
Tell me about the community you work in?
Do you work in the same community in which you reside?
What are the challenges that the communities in which you work face?
Being a community care giver

What is a community care giver?

What are the duties expected of community care givers?

Do the expectations differ from those of stakeholders and those of the community?

Training of CCGs

How does one become a CCG?

What training do CCGs receive?

Experiences of CCGs

What are the tasks performed by CCGs?

How are CCGs treated by the community within which they work?

What are the challenges that CCGs encounter in their work?

How do these challenges affect you?

Coping mechanisms available to CCGs

What support is availed to you and other CCGs?

How do you cope with the challenges that you encounter as a CCG?

What other support mean would you like availed to you?

Closing

The researcher will thank the participants for taking part in the study. She then will ask if there are any questions or comment. She then will remind them of the confidentiality of the study and the limits thereof. The participants will be informed of the further actions of the study.
Information Sheet

My name is Zama Mncube, I am a masters student at the University of KwaZulu-Natal Pietermaritzburg. As part of my degree, I am conducting a study that investigates the psychological impact of community care work on the community care givers. Focus groups will be held where there will be discussions on experiences, challenges and coping mechanisms of community care givers.

**The focus group process**

The focus group will run for about 2 hours. There will be 20 participants in each focus group. Participants are encouraged to freely and honestly talk about their views on the topic that will be discussed in the focus group. There are answer cards provided that participants can write their responses on to asked questions.

Participation in the focus group discussions is voluntary and a participant holds the right to drop out of the study at any point that they wish to.

**Recording the discussion**

A tape recorder will be used to record the focus group discussions, this is to ensure that every detail of what was said is captured, which will lead to more accurate results.

**Confidentiality**

Each participant is required to sign a confidentiality pledge, which binds you to keep the information that is discussed in the focus group confidential.

Your identity will be kept confidential by using pseudonyms (fake names) in the transcription of the interview and in the final research project.

Recordings from this discussion will be transcribed into a written form. In this process I will still refer to you by your pseudonym. The transcriptions may be analysed to gather more information.
or support the information provided on the answer cards. The data for the study will be available to me (researcher), and my supervisor.

Confidentiality pledge: Focus group
As part of your commitment to participate in this study you should hereby agree to keep everything that happens in this focus group confidential. This means that you agree not to talk about any of the issues that were discussed to anyone outside of the focus group or reveal the identities of any of my fellow participants.
You must understand that every member of this focus group has the right to respect and privacy. You should further understand that while the researcher has no control over anybody’s actions, if you break your undertaking of confidentiality that this may have damaging effects on your fellow participants and research in this field.

Data storage
The data collected from the study will be stored in archives for five years and will thereafter be completely destroyed.

Dissemination of findings
Findings from the study will be published in the form of a lay article. They are also going to be used in a PhD study conducted by my supervisor which will be published. No participant names will be mentioned in any of the articles published on the results of this study.

Risks and benefits
There are no physical risks in participating in this study. There only risk is emotional risks which could result if fellow participants would divulge information that was discussed in focus groups. To minimize this, each participant will pledge to keep all information that was discussed in focus groups confidential.

The benefit of participating in this study is information gaining, having the opportunity to discuss and learn from colleagues on their experiences. The results of the study will be great information on experiences of other CCGs in KwaZulu-Natal.
If you have any questions you would like to ask, you are welcome to ask me (the researcher) or my supervisor Nontobeko Buthelezi at 033 2605670, or contact Phume Ximba the Social Science Research Ethics Committee office 0312603587

Your participation is much appreciated

Zama Mncube
0780575365

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Appendix 3
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Consent form
Topic: Community care givers: A thematic analysis of the psychological impact that community health care has on the care givers

What this study is about
This study is about looking at the experiences of community care givers in three different districts in KwaZulu-Natal. The purpose of the study is to understand the experiences of community care givers, particularly the community care givers in some districts of KwaZulu-Natal. KwaZulu-Natal has a rampant statistics of HIV/AIDS, which created a context of different experiences for community care givers in this province. The proposed study aims to understand the psychological impact that working in this context could have on the community care givers. The proposed study also aims to understand the support available for care givers to assist them in coping with the nature of their work.

What participation entails
The participants are in no manner coerced to take part in this study. Participation is completely voluntary and you may pull out at any time if you no longer wish to continue participating in the study.

I will be asking a few questions in the focus group about the experiences of community care givers. You will be expected to provide a verbal opinion and to also write down on answer cards which will be provided. There is no right or wrong answers when answering questions; you are encouraged to actively take part in the discussions. Should there be questions that make you uncomfortable, you are not coerced to answer. A focus group will have 20 participants and will run for about 2hours.
Important to note

Before signing this consent form the participant should make sure that they clearly understand everything that is written in it. If they have any questions they can ask the research student to clarify. This project is supervised by Nontobeko Buthelezi who can be contacted at buthelezin@ukzn.ac.za.

Giving consent

I ________________ fully understand what taking part in this study entails. I am aware of the fact that I can withdraw from participation at any point.

I pledge to not divulge any information discussed in the focus group. I understand that there is a limit to confidentiality in a focus group setting as the researcher cannot guarantee that the other participants will adhere to the conditions of the confidentiality pledge.

I understand that my data will be stored securely for five years and used for future research. I understand that measures will be taken to ensure that my identity is protected and my participation in this research will be completely confidential in this regard. I understand that no identifying information about myself will be published.

Participant’s name: ______________________

Sign: ______________________

In addition to the above, I hereby agree to the audio recording of the focus group for the purpose of data capture. I understand that no identifying information of me will be released in any form. I understand that the recordings will be stored safely and will thereafter be erased.

Participant’s signature: ______________________

Date: ______________________
Appendix 4

Request for permission to recruit.

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To: HOD Mr. Bheki Nkosi
CC General Manager of Ulundi cluster Mr. Lennox Nkosi
CC General Manager of Pietermaritzburg cluster Ms. Nokuthula Khanyile
CC General Manager of Durban cluster Mr. Wilton Magwaza

My name is Zamalotshwa Mncube, I am a Masters student from the Discipline of Psychology at the University of KwaZulu-Natal Pietermaritzburg. I am conducting a study which looks at the experiences of community care givers and the psychological impact that community health care has on the care givers. I would like to request permission to approach the community care givers working under your program (CBWCY) about participating in this study.

If you agree to participate in this study, community care givers will be approached during their monthly contact sessions about participating. Their participation will not disrupt their work/classes in any way. The focus groups will take place after their classes. Care givers will be given a short description of the study and what participation will entail and will be asked if they would like to participate in the study.

If you would like to discuss any further details of my project or have any questions about this request please contact Zamalotshwa Mncube on 0780575365, or my supervisor, Nontobeko Buthelezi on 033 2605670.

Thank you for your consideration,

Regards,

Zamalotshwa Mncube
mncubenomzamo@yahoo.com
Generic schedule

Focus group schedule

Opening

The researcher will introduce herself. She then will briefly talk about the study, and ask if there is anything the participants would like clarification on. She then will highlight the issue of confidentiality and will encourage the participants to express themselves freely and truthfully.

The researcher will then inform the participants about the focus group process and what is expected of them as participants in the study.

The following are questions that will be covered in the focus groups. The participants will be allowed to verbally express their views as well as write down on answer cards their responses to the questions, and at the end of the focus group discussion the participants will then organize the cards into themes.

Background

Aningixoxeleni ngemiphakathi enisebenza kuyo.

Nisebenza emiphakathini efanayo nale enihlala kuyo?

Izipi izinquinamba imiphakathi enisebenza kuyo ebhekana nazo?

Being a community care giver

Yini i-community care giver?

Emphi imisebenzi elindeleke kuma-community care givers?
Do the expectations differ from those of stakeholders and those of the community?

Training of CCGs
Iziphi izinyathelo umuntu azithathayo kuze abe i-CCG?
Yikuphi ukuqeqeshwa okutholwa ama CCG?

Experiences of CCGs
Yimiphi imisebenzi eyenziwa ama CCGs?
Imiphakathi enisebenza kuyo njengama CCGs iniphatha kanjani?
Iziphi izinquamba eni abhekana nazo emisebenzini?
Ngabe lezi zinquamba ziniphatha kanjani?

Coping mechanisms available to CCGs
Yikuphi ukweseka enikutholayo njengama CCGs?
Nibhekana kanjani nezinquamba enibhekana nazo emisebenzini?
Yikuphi okunye ukwesekwa eningathanda kuthi kubekhona?

Closing
The researcher will thank the participants for taking part in the study. She then will ask if there are any questions or comment. She then will remind them of the confidentiality of the study and the limits thereof. The participants will be informed of the further actions of the study.
Appendix 2

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Information Sheet

Igama lami ngu Zama Mncube, ngingumfundisi wase nyuvesi ya KwaZulu-Natal Pietermaritzburg. Nje ngenxenya ye degree yami, ngenza lomsebenzi woncwaningayo ohlose ukucwaninga ukuthi umsebenzi oweniwa onompilo ngabe ubaphatha kanjani. Kuzoba nama focus group lapho kuzoba nezogxoxo ngemisebenzi eyenziwama onompilo, izinqinamba enibhekana nazo, kanye nezindlela enibheka nalezingqinamba enibhekana nazo.

Ingxoxo bandla


Ukubamba ichaza kulezingxoxo akubophezelekanga, wonke umuntu unelungelo lokuyeka ukubamba ichaza kucwaninga mabefisa.

Ukuqophapha amazwi kwlingxoxo

Isiqophapha mazwi sizosebenziswa kulezi ngxoxo ngoba umcwani ufuna ukuqiniseka kuthi yonke iminingwane eshiwo kulezingxoxo iqophiwe, lokhu kwenza ukuthi imiphumela yalocwaninga kube iyonayona ngaphandle kongungabaza.

Imfihlo yemininingwane yabantu

Wonke umuntu ozothatha ichaza kumele asayine ukuthi uyafunga ukuthi ngeke adalula izinto ekuxoxwe ngazo kwlingxoxo bandla.

Ubuninibakho buzogcinwa imfihlo ngokusebenziswa kwesingathEKISO uma sekubhla loku okuphishiwe, namase kubhalwa imiphumela yocwaninga.
Iziqopho zakwi ngxoxo bandla zizobese zibhalwa phansi. Umakwenziwa lokhu kuzosenbenziswa izingathethiso. Lokho okubhaliwe kuzo hlaziywa eminye eminingwane esekela le etholwe kumapheshana okuphedulela.

Ukufunga: ngxoxo bandla

Njengenxenye yokuzinikela ekuthatheni ichaza kule ngxoxo bandla, ngiyafunga ukuthi yonke into okuxoxwa ngayo angeke nyayidalula. Lokhu kusho ukuthi ngeke ngakhuluma ngokwenzekile kwingxoxo bandla kwabanye abantu abangaphandle kwe ngxox bandla, futhi ngeke nga dalula iminingwane yabantu abathathe ichaza kulolucwanningo.

Kwamele uqonde ukuthi wonke umuntu unelungelo lokuthi ahlonishe futhi iminingwane yakhe ihlale iyimfihlo. Uqonde nokuthi ukwephula kwakho lesithembiso sokuthi angeke wadalula okwenzeke kwingxoxo bandla kungaba nemiphumela emibi kubantu ababethathe ichaza kulocwanningo.

Ukubekwa kwemininingwane

Imininingwane etholwe kulolucwangingo izobekwa endaweni ephephile iminyaka emihlanu, emvakwaloko ibese iya destroyed.

Imiphumela yocwaningo

Imiphumela izobhalwa nje ngephepha locwaningong. Izosebenziswa njengenxenya yemiphumela kucwaningo olenziwa u supervisor. Amagama abantu abathathe ichaze angeke adalulwa kumiphumela yocwaningo.

Risks and benefits


Ongakuthola ngokuthatha ichaza kulolucwango ukuthi uthole ithuba lokuxoxa nabanye ngomsebenzi eniwenzayo, futhi uthole nethuba lokufunda kwabanye. Ozokuzuza ukuthola ulwazi ngomsebenzi nezinginamba nokuthi abanye babhekana kanjani nezinginamba emsebenzini wabonompilo ba KwaZulu-Natal.

Umangabe uneminye imibuzo ongathanda ukuyibuza, wamukelekile ukubuza umcwanningi noma uNontobeko Buthelezi at 033 2605670.

Ukuthatha kwakho ichaza kuyajabulelw.

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Appendix 3

Consent form

Isihloko: Community care givers: A thematic analysis of the psychological impact that community health care has on the care givers

Lolucwaningo lumayelana nani.

Lolucwaningo lubheka ama experience ama CCGs kuma district amathathu KwaZulu-Natal. Inhloso yalolucwaningo ukuqoda izimo ama CCGs aKwaZulu-Natal abhekana nazo emisebenzini yabo. iKwaZulu-Natal inabantu abaningi abaphila nesifo sikagawulayo, okwenza izimo onompilo baKwaZulu-Natal abasenza kuzo zihlu futhi zibe nezinqinamba ezahlukile. Lolucwaningo lihlose ukuqonda ukuthi ngabe yimuphi umthelela wenqondo lomsebenzi onawo kuma CCGs. Lolucwaningo lubheka ama experience ama CCGs akutholayo ukuse bakwazi ukubhekana kancono nezimo zasemisebenzini.

Ukuthatha ichaza kusho ukuthini.

Abathatha ichaza abaphoqelakanga ukuthi bathathe ichaza kulomcwaningo. Umuntu uthatha ichaza ngokuthanda kwakhe, futhi uma engasafisi ukuthatha ichaza angahoxisa noma ngabe kunini.

Ngizobe ngibuzo amibuzo emibalwa kwingxoxo yebandla emayelana nezimo onimpilo ababhhekana nazo emisebenzini yabo. Njengomuntu othatha ichaza kulocwaningo, ulindeleke ukuthi uzoxoxa futhi ubhale phansi kumapheshana ezimpendulo imibo yakho ngesihloko ekuzobe kukhulunywa ngaso. Ayikho impendulo ekuyiyona noma ekungasiyona, ngalokho uyakhuthazwa ukuthi ubambe ichaza kulolucwaningo. Umangabe kunemibuzo ekwenza ungakhululeki, awuphoqelekanga ukuthi uphendule. Ingxoxo bandal izoba nabantu abangamashumi amabili abazobe bebambe ichaza, ilindeleke ukuthi ithathe isikhathi esingaka ngamahora amabili.

Okubalulekile kuthi ukwazi
Ngaphambi kokuba usayine lelifomu, qiniseka kuthi uyayiqonde yonke into ebhalwe ngaphakathi. Umangabe unemibuzo ungangabazi ukuba kuwcwani ukuthi akucacisele. Noma ungaxhumana noNontobeko Buthelezi ku buthelezin@ukzn.ac.za.

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Ukuvuma

Mina ____________________________ ngiqonda ngokuphele ukuthi ukuthatha ichaza kulocwangingo kusho ukuthini. Ngiyazi ukuthi nginga hoax ekuthatheni ichaza noma ngabe kunini.

Ngiyafunga ukuthi ngeke ngidadule izinto ezizobe zishiwo kwingxoxo bandla. Ngiyaqonda ukuthi umcwaningi ngeke athembise ngokuphelele ukuthi yonke into eshiwo kungxoxo bandla izohlala emfihlweni ngoba ngeke akwazi ukuvimba abantu abazobe bekwingxoxo bandla ukuthi bangadaluli okwaxoxwa ngako.

Ngiyaqonda ukuthi iminatingwane etholakele ngalolucwangingo luzobekwa endaweni ephiphile iminyaka emihlanu ngoba kungenzeka isebenziswe kusasa. Ngiyaqonda ukuthi iminatingwane yami izohlala emfihlweni nokuthatha ichaza kwami kulocwangingo kuzohlala kuyimfihlo, ayikho iminatingwane engahlanganiswa nami ekuzobhalwa ngayo.

Igama: ____________________________

Sign: ____________________________

Ngaphezu kwalokhu ookubhaliwe ngenhla, ngya vuma ukuthi kusebenziswe isiqopha mazwi okuzosiza ukuthi umcwaningi akwazi ukuphisha iminatingwane ebalulekile. Ngiyaqonda ukuthi iminatingwane yami izohlala iyimfihlo, futhi loko okuzobe kuqophiwe kuzobekwa endaweni ephephile kubese kuyacishwa emvakwaloko.

Sign:

Date: