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THE PSYCHOSOCIAL CIRCUMSTANCES OF COMMUNITY CAREGIVERS: A CASE OF TSHWANE REGION

A research report presented to the school of Human and Community Development

Faculty of Humanities

University of Witwatersrand

In partial fulfilment of the requirements for the degree Master of Arts in Social Work

By

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November 2016

DECLARATION

I declare that this research report is my own work and that all the sources that I have used or quotes have been indicated and acknowledged by a complete reference list.

…… ……

Sophia Ntikane Ntobeng Date

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KEY WORDS

Psychosocial support, circumstances, home and community and based care (HCBC), community caregivers (CCGs) and Non-Government Organisations (NGOs).

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CHAPTER 1

INTRODUCTION AND OVERVIEW OF THE STUDY

1.1 Introduction

In this chapter, the problem statement and rationale for the study will be explained. The purpose of the study and an overview of the research methodology applied will be described. The key concepts will be defined, limitations of the research study will be highlighted and the layout of the research report will be provided.

1.2 Problem statement and rationale for the study

Home and community based care (HCBC) has emerged as a way to provide cost-effective and compassionate care for people living with HIV/AIDS and those affected by the epidemic. This model is practiced worldwide as an alternative to provide care to people requiring extended health care while not necessarily needing hospital or institutional care.

The HCBC organisations focus on orphans and vulnerable children (OVC), people living with HIV (PLHIV) as well as vulnerable households. HCBC organisations provide integrated services that address the basic needs of those infected and affected such as food, shelter, health care, protection from abuse and malnutrition. These integrated services include conducting home visits, providing material and psychosocial support and support groups.

The majority of people rendering HCBC services are volunteers and lay counsellors with minimum training and skills and some of them are also affected and infected. The caregivers are paid stipends as a token of appreciation for the work they do. Besides the payment of stipend, caregivers deserve holistic psychosocial support with regard to the work they do.

It has been observed that community caregivers are not given the necessary support in terms of their psychosocial circumstances. This observation was made through interaction with community caregivers who are unhappy and dissatisfied with various factors of their work, which also affect their families and personal functioning. There have also been numerous reports of suicide and suicide attempts by community caregivers, some of which alluded to their lack of

support and personal circumstances being unbearable. Project managers also complain of mediocre work and caregivers' lack of commitment to their work. Caregivers are only paid a minimal stipend as a means of motivation. However, this does not provide enough motivation for them to perform outstandingly, particularly in lieu of their personal circumstances.

According to (DSD (2012) the provision of psychosocial support for caregivers is important. Community caregivers play a specific role in the interventions to support orphans and vulnerable children as well as their families. The HIV/AIDS pandemic is leaving too many children orphaned and vulnerable, without any visible means of care and support.

Terminally ill parents need care and support and as a result, children, youth and older persons assume the burden of caring for them. HCBC comes about as the best intervention strategy in such vulnerable households. The programme also promotes the option of raising children in their families and immediate communities instead of placing them in alternative care. With reference to the Framework for Home and Community Based Care and Support Programmes (DSD, 2012), the provision of comprehensive and quality health and social services is essential. These include health and social services by formal and informal Community Care Givers (CCGs) in the home in order to promote, restore and maintain a person's maximum level of comfort, functioning and health including a dignified death. It is for these reasons that community caregivers should receive intensive support as they render the most important services to vulnerable households and impact on family preservation, dignity for the dying and bereavement counselling.

The HCBC programme is based on the principle of comprehensive health and social services being provided by CCGs within a family and community context. Thus, people who are infected and affected by HIV and AIDS are not only provided with medical care, but also receive psychosocial support by both formal and informal health and social development workers. The HCBC programmes are supported and appreciated. However, the caregivers are neglected and their psychosocial needs undermined especially by government officials who monitor HCBC and project managers at HCBC organisations acting as employers for caregivers.

The framework for HCBC is based on a holistic care and support model that also addresses the needs of CCGs to promote their overall wellbeing. Non-profit organisations work with volunteers but donors and government departments like Social Development, Public Works, and Health support the NPOs with training and funds for the volunteers, which are much appreciated and also give financial support to enable organisations to render these important services. The World Health Organisation (2002) states that HCBC should not be seen as a cheap alternative to medical care, and emphasises that volunteers should be supported properly and recognised for the work they do. However, despite the monetary support, the community caregivers deserve holistic psychosocial support pending the intensity of the work they do.

The psychosocial support of the care givers is paramount. According to REPSSI (2009, p. 44), "not only do they have to cope with the painful situation of their clients, but many of them are also living with HIV and going through the same situation as their clients. Or they themselves are grandparents taking care of orphans, having seen their own adult children pass away". Therefore, it is important to consider such circumstances and render the necessary support and training to such caregivers in order to support and enable them to deliver effective services to their clients.

The study explored the community caregivers' psychosocial circumstances and elicited suggestions on how to intervene to ensure optimal support to caregivers and services to the client system. The findings of this study provided recommendations in terms of amendments to the Framework for Home and Community Based care and Support Programme, and makes suggestions to influence better practice by the officials responsible for rendering the support programme. It also identified areas for future research.

1.3 Purpose of the research study

The purpose of this study is to explore the psychosocial circumstances of community caregivers working in Tshwane Region. According to DSD (2012), community caregivers need support to do their jobs well, remain infection free and avoid burnout to ensure that the sustainability and quality of their services is not compromised.

1.4 Overview of the research methodology applied

A qualitative research strategy was conducted to explore the psychosocial circumstances of community caregivers. Multiple case study design was applied to collect data through a semi-structured interview schedule. The sample for this study was obtained from one of the largest home and community based care organisations in Tshwane Region that has centres in the three different types of communities to cater for the diversity and uniqueness of the study. Caregivers from this organisation were requested to volunteer to participate, however, the criteria was that they should have at least been working at the organisation for two or more years and they should be older than eighteen years of age. The selection and interviews were done at the different centres, as it would be difficult and costly to gather all the caregivers at the same place. Fifteen participants were targeted but thirteen participated, one declined and the other one did not show up for the time schedule for the interview.

The collected data was analysed through content analysis coded into themes that were analysed and then conclusion derived.

1.4.1 Research question

This study attempted to provide answers to the following questions:

What are the psychosocial circumstances of community caregivers working in HCBC centres in Tshwane Region? How do the psychosocial circumstances of community caregivers influence their work performance and personal lives?

1.4.2 Primary aim and secondary objectives of the study

The primary aim of the study was to explore the ways in which the psychosocial circumstances of community caregivers working in Home and Community Based Care Centres in Tshwane Region affected their work performance and personal lives.

Secondary objectives of the study were to:

1. Explore the psychosocial circumstances of community caregivers.

2. Investigate the challenges that affect community caregivers and engage them in finding solutions.

3. Explain the coping mechanisms that community caregivers apply in balancing their home and work circumstances.

1.4.3 Definition of key concepts

1. Circumstances refer to one's condition or state of wellbeing. In this context, the term refers to the community caregivers' state of well-being due to their working conditions.

2. Community caregiver "is the first line of support between the community and the various health and social development services. He/she plays a vital role in supporting and empowering community members to make informed choices about their health and psychosocial wellbeing and ongoing care and support to individuals and families who are vulnerable due to chronic illness and indigent living circumstances" (Learning about Social care, 2006 in DSD, 2012, p. 7).

3. Home and community and based care (HCBC). Smart in Magezi (2007, p. 180) defines, home-based care as "the provision of comprehensive service (including health and social sciences) by formal and informal caregivers in the home, in order to promote, restore and maintain a person's maximum level of comfort, function and health."

4. Non-Government Organisations (NGOs) are "private, self-governing voluntary organisations that operate in the public interest and not for commercial gain to promote the welfare and

development of society, religion, charity, education and research (White Paper on Social Welfare, 1997 in DSD, 2012, p. 9).

5. Psychosocial support (PSS) means the way we take care of one another. It is about building a relationship of respect and acceptance where the dignity of people is strengthened. PSS services "provide support and counselling to restore the normal functioning of individuals and families by enhancing their mental, social, spiritual and emotional wellbeing" (REPSSI, 2009).

1.5 LIMITATIONS OF THE STUDY

Limitation in this study was race representation. There were only Black community caregivers in the selected organisation. It is a known fact that Tshwane Region has a fair distribution of caregivers including Whites and Coloureds. It is possible that their views and opinions could have been overlooked and omitted in the study.

1.6 Layout of the report

In Chapter 2, the theoretical frameworks forming the foundation for the study are explained and the review of pertinent literature in the field of study provided. In Chapter 3, the research methodology employed in the research study will be discussed. Chapter 4 deals with the analysed data and findings from the research study. Lastly, Chapter 5 highlights the main findings of the study, specific conclusions and recommendations for different structures and possible future research.

CHAPTER 2

LITERATURE REVIEW AND THEORETICAL FRAMEWORKS

2.1 Introduction

There is a paucity of literature and limited research conducted in South Africa on the psychosocial circumstances of home and community caregivers. However, there are studies conducted internationally, for instance in Cambodia, Botswana and one major study in Venda in South Africa.

The theoretical frameworks applicable to this study will outline the meaning, nature and challenges experienced by community caregivers so that better strategies can be found to improve their psychosocial wellbeing. The primary theoretical framework applicable to this study is the Asset-Based Community Development Approach (ABCD). This approach encompasses several other theories such as the strengths based perspective, resiliency approach, social justice, rights-based perspective and compliments sustainable livelihoods.

This section also entails an overview of literature related to home and community based care, how the caregivers are selected, trained, their work evaluated, monitored and supervised. It will also focus on the support of community caregivers as well as their roles responsibilities and contributions in the community.

2.2 Theoretical perspectives underpinning the research study

The theoretical perspective of this study outlines the meaning, nature and challenges experienced by community caregivers. The Asset-Based Community Development Approach (ABCD) appears to be an appropriate framework for the study as it encompasses several other approaches such as the strengths-based perspective, resiliency theory, social justice and rights-based perspective. It also compliments sustainable livelihoods approach.

2.2.1 The asset-based community development approach (ABCD)

This study was based on the Asset-Based Community Development approach (ABCD). According to Pretorius & Nel (2012), the ABCD approach is founded on the essentials of the strengths perspective, which is a collaborative process between community members and the professionals allowing them to work together to determine outcomes that draw on community members' strengths and assets.
This approach focuses rather on what the people are capable of doing as opposed to what their shortcomings are.

2.2.1.1 Characteristics of the ABCD approach

The ABCD supports the bottom-up approach of empowerment. According to Kirst-Ashman (2010, p. 208): "A "grassroots, bottom-up approach" means that the people at the bottom of the formal power structure, such as ordinary citizens, band together to establish a power base and pursue macro changes. Often the focus is on helping individual community residents to strengthen relationships among themselves, develop shared goals and establish coordinated plans to achieve these goals. The focus of change is usually an issue that directly affects the community residents involved". This bottom-up endeavour strengthens self-reliance and sustainability of projects and complements social justice.

Community members focus on their development irrespective of their age, race or gender. It must, however be stated, that women are the forerunners of home and community based care programmes. Most HCBC centres are established and led by women. Very few men participate in HCBC although they play an exceptionally important and visible role especially to the male beneficiaries as well as being role models to male orphans and vulnerable children (OVC). The ratio of men in HCBC as compared to women is very low, this can be attributed to many factors including the cultural expectation of men being providers. Therefore volunteer work is always "stigmatised" and viewed as women's responsibility.

In terms of the ABCD bottom-up approach, the HCBC programmes give relief to the health sector by ensuring that most patients receive assistance at home while the family is also supported. They help the family to deal with the realities of the disease and the evident death and the bereavement process. Members of the community become producers instead of consumers and they actively engage with public and private sectors on a macro level
The ABCD approach focuses on skill and talents in the community. Caring and supporting is an innate asset for women hence they are the main actors in HCBC. A closed community is also good is forming social relationships, which create valuable associations and networks. Within these networks, there are elements of trust and relationships based on trust strengthen the responsible utilization of community resources. ABCD is a practical application of the concept of social capital. Community members share their resources that can be translated from any asset to financial capital. Therefore, one does not need money to afford other physical needs. Participatory approach to community development is central to the ABCD approach (Pretorius & Nel, 2012; Mathie & Cunningham, 2002; Saleebey, 1995).

2.2.2 The strengths perspective

The strengths perspective complements and is encompassed by the ABCD as they have the same views and almost the same characteristics. There is a strong belief that in terms of the strengths perspective, strength-based practices assess the inherent strength of the person or family then builds on them. Strengths based practice uses people's personal strengths to aid in recovery and empowerment.

Healey (2005 p. 15) states, "the strengths perspective focuses on the capacities and potentials of the service users. It concentrates on enabling individuals and communities to articulate, and work towards their hopes for the future, rather than seeking to remedy the problems of the past or even the present". This relates to the ABCD approach in that the strengths perspective also focuses on the capacity instead of the needs.

The strengths perspective argues that clients are motivated to use their capacity to change when the focus is on their strengths. A focus on the strengths does not mean that people's concerns and

problems are ignored, but they are not the focus of the intervention. The strengths perspective suggests that the focus should be more on the person's strengths in order to address the problem not vice versa. That also implies focusing more on the person's tenacity, stability and change. It actually curbs the stereotypes and labelling. People have survived to this point- certainly not without pain- but with ideas, wills, hopes, skills, and other people, all of which we need to understand and appreciate in order to help. Change can only happen when you work collaboratively with clients' aspirations, perceptions, and strengths and when you firmly believe in them. All people have strengths, capacities and resources. People usually demonstrate resilience, rather than pathology, in the face of adverse life events. Saleebey (1992a) states that clients have taken steps, summoned resources and coped. We need to know what they have done, how they have done it, what they have learned from doing it, who was involved in doing it, what resources (inner and outer) were available in their struggle to surmount their troubles outlines five key assumptions from the work of (Healey, 2005; Saleebey, 1992a; Saleebey, 1996; Saleebey, 1997; Weick et al, 1989).

The strengths perspective can thus be seen as the approach to reinforce and appreciate the person's ability to survive instead of what can be done to make then survive.

2.3 Literature review

2.3.1 What is Psychosocial Support?

Psychosocial support (PSS) means the way we take care of one another. It is about building a relationship of respect and acceptance where the dignity of people is strengthened. Repssi (2009, p. 7) stipulates: "PSS is about helping children, families and communities to improve their psychosocial wellbeing. It is about encouraging better connections between people, and building enhanced sense of self and community". Therefore, community caregivers, like all other recipients of psychosocial support services also deserve the same treatment. They should be valued, listened to and treated with courtesy and respect. There should be wide range of care, support and protection activities that focus on enhancing the social, spiritual, emotional and psychological wellbeing of community caregivers, their families and communities.

2.3.2 What is Home and Community Based Care?

In its original form, volunteers who were concerned about the living conditions of people with disability and chronic disease after the Second World War started the concept of home and community-based care. People who were injured needed assistance to cope with the disability they incurred or living with long-term illness. The WHO (1990) termed the concept of care *Disability Adjusted Life Years* (DALY). With the rapid spread of HIV/AIDS in the developing countries and specifically in South Africa, more and more people needed care and support.

Therefore, the DALY model still applies, as people living with HIV (PLHIV) are usually too sick to take care of themselves and their families. When they get to a state where their CD4 count is too low, the government gives them temporary disability grant, because they are unable to fend for themselves. This is the stage where home based care is essential, to assist and educate the family on how to take better care of the patient and themselves. They need more emotional support and preparation for the worst scenario when the patient dies and the subsequent grief and bereavement counselling.

REPSSI (2009, p. 4) summarises the definition of home-based care as "the care and support that people living with HIV and AIDS and other chronic illnesses receive in their homes, through their families and communities." This care includes medical, nursing, emotional, spiritual, psychological, social and material needs of people living with HIV and AIDS and their families.

This implies care given in the home and community of the beneficiary. Smart in Magezi (2007) notes that home-based care is the provision of comprehensive health and social sciences by formal and informal caregivers in the home, in order to promote, restore and maintain a person's maximum level of comfort, function and health. These services are just not needed for end of life care, but throughout the course of illness. Due to limited resources, the South African health care system cannot handle the growing need for health care therefore, hospitalisation has become discriminatory where people especially those suffering from HIV/AIDS related diseases are refused admission or discharged earlier.

HCBC is therefore one of South Africa's strategies to respond to the triple challenges facing the sub-Saharan Africa, namely, providing adequate health care services, reducing new HIV infections and coping with the aftermath of the millions of AIDS related deaths. According to Uys (2003, p. 3), "Home-care started in North America and Europe when it became clear that hospital care was too expensive, and that families and other carers found it difficult to cope on their own with the demanding care of people living with HIV/AIDS (PLHA)".

Terminally ill parents place the burden of care on the children, youth, and even grandparents. For these vulnerable households, home and community-based care and support programmes are very essential as they help with dealing with death, the dying and bereavement processes and they become support systems in the child, youth and granny headed households.

DSD (2012), describes HCBC as the provision of comprehensive and quality health services in the home and community to promote, restore and maintain a person's optimum level of comfort, social functioning and health. In an effort to address the HIV/AIDS pandemic the government of South Africa in its National Action Plan acknowledges the vision of the Framework for Home and Community Based Care and Support Programme. This is to establish communities that are able to support and care for individuals and families and competently manage the health, social and economic consequences of all chronic conditions. Furthermore this vision entails the promotion of the continuum of care and strengthening family support systems. The vision can best be achieved through the implementation of home and community based care services.

According to Uys (2003, p. 5), the advantages of home-based care include inter alia the following: "It allows the patient and the family time to come to grips with the illness and the impending death of the patient. It is less expensive for the family because problems such as transport to hospital, time spent on hospital visits, and other costs are reduced. Relatives can take care of the patient while attending to other chores. Care is more personalised, and the PLHA feels less isolated from family and friends. People prefer to face ill health and death in familiar surroundings rather than in a hospital ward. The totality of care is less expensive for the country than institutional options, since periods of hospitalization are reduced".

Non-Government Organisations (NGOs) play an important role in the concerted effort to fight the HIV epidemic. One of the advantages of Non-Profit Organisations (NPOs) in the development process according to Davids, Theron and Maphunye (2009. p 70) is that "they are effective in assisting the poor to participate in matters affecting them and to thus gain more control over the quality of their lives. The ability of NGOs to promote public participation is due to their partnership relations with the communities they serve". Despite the limited funding by government and donors to NGOs, community caregivers remain committed to service rendering by continuing to volunteer their services. That is exactly what the Asset Based Community Development approach advocates for, the principle of "Ubuntu", which means being neighbourly.

Most of the community caregivers live in relative poverty and are mostly dependent on social grants. Swanepoel & De Beer (2001, p. 2) state that relative poverty "refers to people whose basic needs are met, but who, in terms of their social environment, still experience some disadvantages". Despite their circumstances, the individuals who are willing to be caregivers contribute to human capital by volunteering their skills and availability in their respective communities. The fact that they are part of the community enables them to be part of the community assets despite the fact that they never had the opportunity to develop themselves for better living conditions. However, most of these volunteers are now getting the advantage and privilege through the Extended Public Work Program (EPWP) to obtain accredited training as child and youth care workers.

2.3.3 The selection of community caregivers

Community caregivers initially start working at NGOs as volunteers. There is no formal qualification required to be a volunteer except police clearance to confirm that the person has never committed any crime particularly against children as required by the Children's Act of 2005. According to Rendall-Mkosi and Phohole (2005, p. 9) "volunteer care workers are selected

by the community in which they live. They are mostly mature women who are willing to walk to patients in their own village, and are given a stipend of R300 a month. Their educational level varies from no schooling to post-matric". This is still the case today, and progressively care giving is becoming more of a profession and young people are joining in. The minimum stipend paid to volunteer caregivers is currently R1500, 00 per month, and for the qualified CYCW is about R5500, 00 per month. NGOs that have large donors pay even more.

The WHO (2002) stresses the importance of honouring community caregivers and acknowledging their importance in the health system. They should receive training in CHBC and some form of incentive. The choice of incentives is determined by the community and financial status of the CHBC programme and might be an honorarium, in kind payment, uniforms, badges or T-shirts.

The DSD (2012, p. 47) outlines the following selection criteria for home and community based caregivers: "be at least over 18 years of age; be a South African citizen or at least have the permit to reside or work in South Africa; must have no criminal record, especially records associated with abuse of children and elderly; be someone who does not have a permanent job elsewhere; be willing to learn more and become committed to the fight against HIV and AIDS, and other chronic conditions, and any other social ill; be willing to commit time in carrying out the activities of the programme; be trustworthy; approachable and easy to communicate with; be mentally stable; have values that do not clash with community values; be prepared to uphold principles of confidentiality; be willing to be held accountable by the Management Committee and the community at large in all interactions; be willing to sign a commitment form that binds him or her to treat children and families placed under his or her care with dignity, respect and honour they deserve". These criteria should form the basis of employing any caregiver anywhere in the country. They are in line with the Constitution; The Children's Act 38 of 2005 and covers the Batho Pele Principles of Service Delivery.

The South African criteria are also in line with the WHO (2002, p. 60) hiring criteria, which stipulate, "members of the CHBC team should be recruited based on established professional

qualifications, knowledge and demonstrating empathy, being sensitivity, having a non-judgmental attitude, practicing confidentiality and demonstrating motivation are important qualities that are considered when selecting caregivers. These criteria are outlined in the norms and standards manual for Home and Community Based Care compiled by the HIV/AIDS Sub-Directorate of the Department of Social Development.

2.3.4 Training of community caregivers

All the volunteer community caregivers who have passed matric are selected and sent for training which the Expanded Public Works Program (EPWP) funds. DSD, 2012 states that training and capacity development of staff should include training based on registered unit standards and aligned with a minimum skills set that include the recognition of prior learning process; regular supervision of community caregivers; and a database of accredited service providers and courses offered.

Uys (2003, p. 9) states, "because of the complexity of the counselling and physical needs of clients, a training period of at least three weeks is recommended. After training, they should be allocated to a specific area, and a professional should supervise their work, if possible. This will not only promote quality of care, but will also act as support for the CCG. This is an emotionally demanding job, and support of the CCG is essential". The actual status quo in Tshwane Region is that caregivers are not receiving the stipulated supervision. They are mainly supervised by the project managers, and the majority of them have never received proper management training. These managers have limited knowledge of psychosocial support and related subjects. The DSD norms and standards state that caregivers should be supervised by qualified Social Auxiliary Workers who are registered with the South African Council for Social Services Professions (SACSSP). The social auxiliary worker should also run support groups of the caregivers and manage the caseload, including referrals to social workers. The SACSSP on the other hand stipulates that Social Auxiliary Workers should work under the guidance and supervision of a qualified Social Worker. This ensures proper supervision and support and clear lines of command. However, very few HCBC centres cannot afford the services of social workers.

The criteria for selection for training in child and youth care work is that they should have grade twelve qualification and must have been working as a volunteer at the organisation for at least two years. In South Africa, The National Association offers the training of community caregivers for Child and Youth Care Workers (NACCW) in terms of the Isibindi Model of care. The other type of training is called Thogomelo model of care, which is conducted by National Development Agency (NDA), USAID and other accredited service providers. These models are both skills development programmes and focus on strengthening child protection issues and support to caregivers. The difference between these two types of training is that the Child and Youth Care Workers (CYCW) are accredited by HWSETA and also recognised and registered by the South African Council for Social Services Professions. Thogomelo on the other hand is accredited but not recognised as a profession but as skills development. The other difference is that the CYCW should have passed grade twelve whereas it is not the case with Thogomelo.

Cameron (2003, p. 33) states, "it is essential that community caregivers (CCGs) receive proper training to provide a high standard of care. If caregivers are not equipped with the knowledge and skills they need, they will not be able to function as part of the health care team, and the home-based care programme will not succeed". Recently the South African Qualifications Authority (SAQA) has implemented the criteria and framework for Child and Youth Care Workers to be recognised as Social Services Professionals and after completion of their training; they are required to register with the South African Council for Social Service Professions.

The Isibindi model came about as an important milestone for HCBC caregivers although it still needs to be restructured and integrated accurately into the system. However, there has been challenges and misunderstanding by many project managers on how to implement the child and youth care work versus the ordinary care giving. There is also friction between the CYCW and the volunteer caregivers due to the disparity in the amount of stipends. The CYCW are paid a higher salary while the amount and type of work to be done by the two groups remains the same. There is also a complain about the confusion caused by the NACCW mentors of the CYCW as

interfering with the mangers' work and giving conflicting instructions to the CYCWs. The other complaint is the amount of paper work or administration that is added to the organisations in terms of reporting to the Department and the NACCW.

The DSD took the first cohort of qualified CYCWs and the majority of them work for the Department. Therefore, most NGOs are still functioning with unqualified volunteers while the Department on the other hand has qualified child and youth care workers who have no role to play and no value to add to the system. The CYCWs are currently conducting household and community profiling which does not necessarily need specialised training and specific qualifications. Most of them are already feeling frustrated and misplaced or lost in the system. In Tshwane Region, only ten of the forty-three funded organisations are appointed Isibindi sites where the qualified CYCWs are placed to implement the Isibindi programme. This is not sufficient, as the majority of the OVCs are not covered by the programme. The number of child and youth headed households is increasing, which implies that the services should also be extended.

It is argued by Uys (2003, p. 12), that "A great deal of training is invested in home-care volunteers [which] gives them additional skills and confidence and, in some instances makes them employable". However, this is contrary to the situation discussed in the preceding paragraph where the Department of Social Development is training and retaining the qualified child and youth care workers but is not utilising them optimally thus defeating the purpose of training. The CYCWs get the opportunity to earn proper salaries at the Department whereas the mandate of caring for the vulnerable is defeated. It is believed that they can be placed at the HCBC and still earn the salary they get form the department but most importantly render the necessary services where appropriate.

The guidelines for training of volunteers according to WHO (2002) are: basic information on HIV/AIDS transmission and how to prevent it; basic comfort measures and nursing care for adults and children; managing symptoms and administering medication; use of traditional remedies; universal precautions; palliative care, including counselling terminally ill people,

bereavement counselling and pain relief; nutrition; psychosocial support and counselling for ill people, caregivers, orphans, health and social welfare workers and volunteers.
These guidelines are almost similar to those of the Isibindi and Thogomelo models however they would be more helpful if they can be adapted to suit the South African context of diverse language, religious and cultural groups. This can be done by translating the manuals into the various official languages and incorporating cultural issues accordingly, for example religions backgrounds and traditional beliefs. It can also be useful if the guidelines can be included in the curriculum for support groups of patients and families. The training should encompass supervision and management; stress management as well as care for the carers.

2.3.5 Roles, responsibilities and contributions made by community caregivers

The Isibindi and Thogomelo models require that child and youth care workers work in the life space of the child. This implies that the caregivers must work closely and precisely where the child is at the time, which is at home and/or in safe parks. The Isibindi model complements the ABCD approach by playing an important role in family preservation. The community caregivers live within range of their beneficiaries; therefore, they can render the much-needed home-based services effectively and efficiently. These Isibindi programme focuses on the six goals of family preservation as stipulated by Kirst-Ashman (2010, p. 252) " protect children; maintain and strengthen family bonds; stabilize the crisis situation; increase the family's skills and competencies; facilitate the family's use of a variety of formal and informal helping resources; and to prevent unnecessary out-of-home placement of children". The model advocates for flexi hours so that where necessary, the caregivers should be there early in the morning to see the child through preparation for school and in the afternoon to help with household chores as well as teaching the children to cook and prepare for the next day. These models promote adult supervision and mentoring of child and youth-headed households. There is however, a challenge with effectiveness due to high caseloads. The caregivers are overloaded with more responsibilities with no resources. For instance, they do not have transport; therefore, they have to walk from house to house, which are obviously far apart. They do not have work cell phones or airtime allowance; therefore, they cannot communicate effectively with their clients to make appointments and follow-up.

Anova Health Institute (2014), one of the training service providers that is responsible for strengthening and supporting the public healthcare system through technical assistance. Providing capacity building, clinical expertise and facilitating health technology expansion to the community caregivers adds, "The volunteers supervise the treatment of patients living with terminal illness so that they can live healthier and longer lives. They serve as counsellors, helping poor patients overcome the barriers that prevent them from seeking vital health care, e.g. transportation, lack of awareness, fear and health care costs. The caregivers help the beneficiaries by collecting their medication for them or even arrange transport or accompany them to the clinic." However, the lack of resources hinder this service as sometimes they need transport fares to the other services or the caregiver has to walk long distances assisting the beneficiaries in there regards.

In the USA, Allies for Change, which is a network of educators and activists, who share a passion for social justice and a commitment to creating and sustaining life-giving ally relationships and communities, commented that caregivers comprise of local community members who have certain advantages in their work? For instance they can easily communicate with and gain the trust of their beneficiaries, can develop culturally relevant and highly accessible materials and information and they can adapt the systems to better suit their beneficiaries needs. This is the exact practice in the South African context as most caregivers live in the same communities with their beneficiaries and therefore understand the community dynamics. On the contrary, it causes conflict and challenges to some caregivers due to their age or other weakness that the beneficiaries know about the caregiver.

In their endeavour to render quality services, community home based caregivers encounter problems and barriers which include structural problems, lack of resources, lack of transport money and very low stipends, supervisors' lack of management skills and not being welcome by patients and family members (Moetlo, Pengpid & Peltzer, 2011). Working with such barriers add more strain to the caregivers the same way as the actual work itself, because that render them incompetent and inefficient. Being unwelcomed is unsafe and traumatic as some are threatened and even assaulted.

Community caregivers by virtue of originating from within the community offer more to the health and social system. For instance, they help in raising awareness of the services of the HCBC and the fact that they know the community dynamics help them carry their intervention with ease. “Community volunteers usually form the backbone of the CHBC team. They live in the communities and know the population well” (WHO, 2002, p. 64). They can easily relate and associate with the beneficiaries and they know the diversity in the community.

2.3.6 The psychosocial support of community caregivers

The components of support outlined in the DSD framework entail the importance of psychosocial support of caregivers. The nature of caregivers’ work subjects them to emotional and psychological stress. Therefore, intensive psychosocial support should form the basis of their care and support programme instead of complaints of poor performance, mediocre work and staff turnover. During the 2014/15 financial year, there were numerous repeated reports of suicide and suicide attempts by caregivers in Tshwane Region. Some of the reasons mentioned during intervention are lack of moral support, high caseload, high expectation with lack of training, little or insufficient income and family problems.

DSD (2012) highlights that community caregiver’s work under stressful conditions, which may lead to disillusionment and burnout. They need support to do their jobs well, remain infection free and avoid burnout to ensure that sustainability and quality of their services are not compromised. In Tshwane Region to be specific, it has been observed that the department gives little attention to the psychosocial wellbeing of the caregivers; most of the contacts and training are focused on project managers, social auxiliary workers, as well as board members, while ignoring the real grass root workers.

The WHO emphasised that HCBC should not be seen as a cheap alternative to medical care. They emphasise that volunteers should be recognised and appreciated for the work they do.

According to WHO (2002) "providing volunteer support and care has proved to be essential elements of recruitment and retention in the HCBC programme. Volunteers are paid a stipend and receive psychosocial support and health care. Furthermore, besides the payment of stipends, honouring HCBC team members is another form of retention and motivation". The government's strategy of training community caregivers to be recognised as profession social services professional adds enormous value to their integrity and identity and assists with retention and motivation. The graduation ceremony that is conducted for the CYCWs is motivating and gives them dignity and appreciation especially by the senior government officials that attend and conduct the ceremony. Supplying caregivers with extra incentives and branded promotional materials like T-shirts, uniforms, bags, umbrellas, badges, etc. makes them identify and own their organisation thereby increasing their morale. Another strategy to help to support, motivate and encourage CHBC team members include providing support group sessions, addressing stigma, staff rotation, respite care and honouring CHBC team members in public gatherings.

The Children's Act, 38 of 2005 and simplified policies like norms and standards for home and community based care give clear guidelines on the functioning of the home and community based care services to prevent problems. For instance, Uys (2003) mentions "job description for CCGs; conditions of service of CCGs; financial policy; policy on confidentiality and disclosure; care policies, for example guidelines for dealing with specific symptoms, and referral policy between different service components". However, due to lack of proper supervision and support, the CCGs tend to be do it all by themselves for instance there is usually little or no referral to other service providers and overtaking statutory roles that are outside their scope of work. On the contrary, other services providers seem to undermine the integrity of CCGs thereby refusing to service those referred to them.

Support also entails caring for the caregivers. It has already been mentioned that caregivers deal with sad, painful and dire situations every day. Having to work with the dying, dealing with the grieving family puts a lot of emotional strain on caregivers. They end up depressed and burned-out. It is therefore vital to incorporate 'care for the caregiver' into the home-care programme. Defilippi (2003, p. 28) suggests "Fixed debriefing time needs to be scheduled with a suitably

experienced and qualified professional, skilled in giving psychosocial support. It is simultaneously necessary to adopt a flexible approach to be able to respond to the needs of specific individual caregivers. Employed caregivers should receive personal/emotional supervision during work hours".

Therefore, care for the caregivers programme is very crucial to their psychosocial wellbeing. It is suggested that caregivers can also form their own support groups where they make time to debrief each other and share their experiences and challenges. In 2013, the researcher established a psychosocial support forum for all community based caregivers, including those working in unfunded organisations to afford them a platform for the opportunity for their psychosocial support. The ultimately idea is to establish sub-groups in the various areas due to the size of the region and the number of caregivers, which makes it impossible to gather them in one place at the same time.

REPSSI (2009) suggests that with an explicit psychosocial support focus, the home and community based caregivers can start their own support groups, build support networks and focus on their own professional development to increase their competency. This means, caregivers will not remain complacent and dependant on project managers at NGOs for their wellbeing. A well-structured and functional psychosocial support programme is likely to increase competence, strength and independence. Therefore, the vision and mission of the HCBC programme will be accomplished.

Supervision of caregivers can be seen as another form of psychosocial of support. Caregivers, who are mostly lay people and have not received formal education need a qualified, professional supervisors to oversee their work and assist them through their service rendering and their own psychosocial wellbeing. The Guidelines on Psychosocial Support for A supervisor, according to Adults living with HIV and AIDS and other Chronic Conditions (2010, p. 22) is defined as "a person who is more experienced, highly skilled person than the case manager, who serves as an advisor, quality assurer, confidant and support system to the case manager who assists with challenges and issues that may arise during individual or family sessions."

Supervision does not only apply to the overseeing of the work done. It is also beneficial to the supervisee who in this instance is the caregiver. The Guidelines on Psychosocial Support for Adults living with HIV and AIDS and other Chronic Conditions (2010) adds that the supervisor helps the case manager to deal with emotions that are interfering with the helping process; making sure that the case manager is right on track and is delivering according to the client's needs and the developed IDP; provides the case manager with new techniques and strategies; this helps especially when the case manager gets stuck with the client; provide support; provide expect information; and provides answers to questions that the case manager has no or limited knowledge of". In Tshwane Region for instance, the issue of lack of quality supervision is always raised in the psychosocial support forum established and managed by the researcher. The caregivers are concerned about the level of competency of project managers who tend to be supervisors by default. Not all organisations have social auxiliary workers whose task it is to supervise the caregivers in terms of the norms and standards for HCBC. Therefore, the project manager most of the time not so educated tends to take over the role thus doing disservice to the caregivers, which causes frustration and despondency.

According to Cameron (2003) supervisors should be professional people with a good understanding of community-based care; have leadership and organizational skills; have the ability to commit the necessary time to the caregivers; have the experience and interest in facilitation, mentoring, and counselling, and have access to psychosocial support themselves. An efficient supervisor is likely to nurture and mentor the caregivers, identify and address problems areas in advance, thus strengthening their psychosocial wellbeing and performance.

The Integrated Community-Based Home Care model insists on professional supervision of lay people working with PLHA. Uys (2003, p. 1) argues, "Supervision indirectly benefits PLHA, in that its main objective is to mentor and nurture caregivers so as to prevent burnout and renew and replenish them emotionally and spiritually. They, in turn, are then able to empower and support the primary caregivers in the home and maintain their sense of vocation." This actually denotes that proper supervision of caregivers is dually important for the beneficiaries as well,

because an emotional and psychologically healthy caregiver is likely to see and hear beyond the presented problem thereby rendering optimal service.

2.3.7 Monitoring and evaluation of community caregivers

There are limited psychosocial support programmes for community caregivers and monitoring and evaluation is neglected. DSD (2012, p. 9) defines monitoring as the routine process of data collection and measurement to determine progress of the programme. While evaluation refers to the time bound exercise that systematically and objectively assesses the relevance, performance, challenges and successes of a programme. There is a gap in the framework in this regard, as they do not address the monitoring of the psychosocial programme. There are no proper monitoring systems in place to track the psychosocial support of community caregivers as stipulated in the Framework for Home and Community Based Care and Support Programme.

2.4 Conclusion

The theoretical perspectives applicable to this study have been explored and the Asset Based Community Approach came out as the most relevant and it encompasses other approaches like the strengths, the social justice, as well as sustainable development. The two questions of what psychosocial support and home and community based care were also explored and answered. The selection and training of community caregivers as well as their roles, responsibilities and contributions were also highlighted. The chapter also explored the psychosocial support of caregivers as well as their monitoring and evaluation. The next chapter looks at the research methodology applied in this study.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

This chapteroutlines the specific research methodology that was applied during the research process. The qualitative research strategy used and multiple case study design applied are explained. This chapter further provides explanations on the population, sample and sampling procedures and what research instrument were used. Research methods used when data were collected and analysed are also described. The trustworthiness of the study is discussed, followed by ethical principles considered during the study.

3.2 Research strategy

3.2.1 Qualitative approach

A qualitative research approach was used in this study. According to Creswell (2009), qualitative design is a means for exploring and understanding the meaning of how individuals or groups ascribe to a social or human problem. The qualitative research approach was useful for this study because the researcher sought to explore the participants' psychosocial circumstances and how they affect their performance at work. Furthermore, the coping mechanisms they use to balance their home situation and work challenges where explored.

Ritchie and Lewis (2003) state that qualitative research aims at providing an in-depth and interpreted understanding of the social world of research participants by learning about their social and material circumstances, their experiences, perspectives and histories. This approach allowed for the collection of rich data that provided explanations of social phenomena and their contexts.

The qualitative approach was instrumental in outlining the reasons stated by Greenstein, Roberts and Sitas (2003): "Insider perspectives; thick descriptions; Context sensitivity and inductive

approach" the community caregivers were instrumental in sharing their experiences and opinions in answering the research aims and objectives regarding their psychosocial circumstances. Quotations from the transcripts were used to give a voice to the participants as well as to provide a richness of data. Literature review was helpful in placing the participants and their experiences within an existing body of knowledge both in South Africa and internationally, as well as acknowledging that this case study was context specific and experiences may differ elsewhere. Finally it is a theory is built from the ground up which was encouraged through thematic analysis that highlights themes in relation to the objectives of this study.

3.2.2 Case study design

In pursuing the qualitative research, a case study design was appropriate to capture the meanings and feelings of the participants. According to Fouchè and Schurink (2011, p. 321) "the case being studied may refer to a process, activity, event, programme or individual, or multiple individuals. It might even refer to a period of time rather than a particular group of people. The exploration and description of the case takes place through detailed, in-depth data-collection methods, involving multiple sources of sources of information that are rich in context." In using case studies, the researcher was able to collect detailed data from the community caregivers from their different backgrounds while doing the same jobs.

A case study is based on the constructivist paradigm, which encourages an understanding of reality as relative to and socially constructed by the individual (Baxter & Jack, 2008). By employing this strategy, the researcher was able to get to understand the participants' psychosocial circumstances on a deeper level and able to explore their experiences, feelings and perceptions of the work environment and how it affects their home and personal lives.

Case study design can take the form of single or multiple case studies. In this study study, multiple case study design was applied. One issue of concern was selected but multiple cases studies were used to illustrate the issue. Often the inquirer purposefully selects multiple cass to

show different perspectives on the issue.(Creswell, 2007). The researcher used semi-structered interview schedule to collect information from the four diferent sites of the same organisation. The researcher then analysed the data holistically and then focussed on the themes tounderstand the complexity of the case. This method of data analysis gave a rich context of the case that was investigated.

3.3 Population, sample and sampling procedures

3.3.1 Population

The population for this study was community caregivers from all the 43 funded HCBC centers in Tshwane Region. The centers are spread across all the three types of communities in the region, which are urban, rural and informal settlements. The region has 989 (nine hundred and eighty-nine) caregivers, 56 have been trained for Isibindi, and 36 are already accredited and work as CYCW while 20 are in the process of completion and accreditation. The fourteen participants were sampled from this community of 989 caregivers in the region.

A population refers to the wider group that a study is attempting to investigate. A sample is taken from the general population in order to understand this population better and draw generalisations, where possible, for the wider population (Mason, 1996). Sampling is necessary as it is generally understood that studying the population in its totality is either impractical, impossible or unnecessary. Decisions about the population and sample will hint at the nature of the interest a researcher has (Mason, 1996).

Babbie and Mouton (2001) state that population is the aggregation of elements from which the sample is actually selected, while Neuman (2000) defines population as the name of the large general group of many cases from which the researcher draws a sample.

3.3.2 Sample and sampling procedures

Non-probability sampling was employed in this study as it is commonly used in qualitative research. Non-probability sampling refers to a sample which has not been chosen using random sampling methods which implies that certain units in the population are more likely to be chosen than others (Bryman, 2004). Purposive sampling, as a type of non-probability sampling was chosen due to the relevance this population has to the phenomenon under study.

Purposive sampling is used when a sample is chosen for a specific reason to provide insight into a particular field of interest and is determined by the research topic (Bless et al, 2006). Applying the purposive sampling method allowed the researcher to access more insight to the psychosocial circumstances of community caregivers from different backgrounds.

A sample of 15 caregivers was drawn from one of the largest organisations that has centers in all the three types of communities. The researcher used judgment to obtain the required characteristics of inclusion for the purposive sampling. The criterion was that five volunteers who are over eighteen years of age and have been working for two or more years represented each center. There was however, an exception with one centre as there are only six community caregivers, therefore they were all invited to attend the briefing session and one participant declined to participate therefore leaving five to continue.

The researcher negotiated access to participants through management of the NPO. Permission letters from the NGO as well as from the Department of Social Development as the major funder of the organisation (Appendix D and E). The researcher arranged to meet with all potential participants at the various centers as they are further apart and it is impractical and costly to meet at one venue. The research study was extensively discussed and what the interviews will entail was elaborated upon. The researcher explained that this was a research study to explore their psychosocial circumstances and how that affect their work and home situations. It was explained that there is nothing that the resaercher is going to do with the information, meaning that she will

not intervene or start addresing their problems. this is only meant for study purposes. No incentives were promised nor threat to non-participation made. The management will not be involved in the study and feedback will be given in a summary form with no identifying detils of the particpants or the organisation. The participants' information sheets (Appendix A) and consent forms (Appendix B) were distributed and explained to those who were interested and the participants were requested to hand consent forms back. Only individuals who provided information were involved in the study.

3.4 Research instrument

3.4.1 Semi-Structured Interview Schedule

A semi-structured interview schedule was used to collect data. Greef (2011) in De Vos *et al* (2011) state that semi-structured interviews are defined as those organised around areas of particula interest, while still allowing considerable flexibility in scope and depth. This provided the researcher with a set of predetermined questions that were used as an appropriate instrument to guide the participant. The semi-structured interview schedule comprised open-ended questions that gave the participant liberty to elaborate and the interviewer could probe for more information. Creswell (2003) states that semi-structured interviews are in-depth interviews, often called a conversation with a purpose because they have pre-set questions, but also allows more scope for open-ended questions. The interview schedule for this study began with background information on the participant to provide some context. An advantage of this type of instrument is that the participant can answer any question on the schedule at any time as the interviewer can probe and manages the intensity of deviation. This method is flexible and gives the participants the opportunity to give the full picture of their story.

The questions were designed and formulated according to the research question, primary aims and secondary objectives of the study (Appendix C). The participants responded mainly in isiNdebele (Nguni) and Sepedi (Sotho) and it was later translated into English during the transcription. The interviews were tape recorded with consent in order to keep concentration and

avoid missing some data during note taking or misunderstanding the language. This also enhanced the trustworthiness of the research study.

3.4.2 Pre-testing of the research instrumentation

Pre-testing the research insrument is a way of determining whether the instrument is appropriate, understandable and will yield the desired results. It is a mesure of reliability and a way of ironing out inconsistencies. It is experimenting with the different styles of questioning and determining if it is necessary to follow the flow of the schedule or it can be spontaneous. Pre-testing also helps the researcher to improve their interview skills and identify mistakes in advance to prepare better for the actual interview (Silverman, 2010; Strydom & De Vos, 2002).

The research instrument was pre-tested with three participants from another organisation that was not part of the research study. The participants of the pre-test had the same characteristics as the main participants..The pre-test of the instrument yielded the desired responses. The pre-test participants were later asked to give feedback about the interview and they all in their individual sessions agreed that it was relevant and it also shed light onto issues that have been affecting them negatively but what they never knew what to do. Two of them requested intervention to deal with their issues. They were referred to another social worker who was contracted for the pre-test debriefing. The results of the pre-test are not included in this study.

3.5 Method of data collection

One-to-one semi-structured interviews were used as a method of data collection. According to (Creswell , 2014), these interviews involve semi-structured and generally open-ended questions that are few in number and intended to elicit views and opinions from the participants. Greef (2011, p. 342) states that interviewing is the predominant mode of data or information collection in qualitative research. Researchers obtain direct information through direct interchange with an individual or a group that is known or expected to possess the knowledge they seek.

The use of semi-structured interview schedule allowed for probing, elaboration and expanding to obtain more information while staying on track of the aim and objectives of the study. It is also important that the interview schedule remains short and precise in order to give the process structure and flexibility. In order to elicit enough information, the researcher gave the participants enough time to tell their stories in a safe and comfortable environment. According to Creswell (2014, p. 191) "interview allows the researcher control over the line of questioning". The interview sessions lasted between 20 and 55 minutes per participant and the interviews were captured using a tape recorder. The time spent with each participant depended on the years of experience, age of the participants and the level of comfort they had to tell their stories and ask questions to the researcher.

The nature of the interview and the material covered necessitated tape recording which the researcher obtained permission to use during contracting. Tape recording is essential in data collection in that the researcher can capture more information without missing out something while writing. However, the researcher also took field notes to capture some of the information especially non-verbal cues that cannot be capture in the tape. Note taking is encouraged by Henning (2004) because the researcher may write down certain factors not implicit in the talking, such as body language and gestures, and also helped the researcher to keep track of questions asked and questions needing elaboration.

There was however some level of discomfort with the interview venue at the first site. There is limited office space therefore the interviews were conducted in a hall partitioned with boards and there was lots of noise from the other side where the rest of the staff sat. However, the noise was a also beneficial as there was an asurance that no one could overhear the interview conversation. The other two sites were very quiet and allowed for discussion with no disturbances. The researcher transcribed the audiotaped interviews verbatim at a later stage with reference to the field notes taken.

3.6 Method of data analysis

Data analysis can be defined as the process of bringing order, structure and meaning to all the mass of data collected (Schurink, Fouche` and De Vos, 2011). Qualitative data analysis is often a complex process that is not easily formulated. Whereas quantitative data analysis has clear cut rules and formulas, qualitative analysis focuses on understanding the themes that come through in the narrative. "Qualitative data analysis is a search for general statements about relationships and underlying themes; it explores and describes and builds grounded theory" (Marshall & Rossman, 2011, p. 207). Data analysis is the process that tries to make sense of the text data and by preparing this text and conducting analysis, a deeper understanding is gained of this data and interpretations of it can be made (Creswell, 2009).

Transcribing the interviews was an important first step and this not only helped get the interviews onto paper, but also helped remind the researcher of what was covered in each interview. The researcher read through all the transcripts to get a general sense of the participants' views and experiences and then reflect on its overall meaning. The organisation of transcripts involved preparing the data, coding the data and developing themes and descriptions which were analysed and explored critically. There are a number of processes involved in analysis: it is an ongoing process which requires constant reflection, organising and writing; it involves collecting open-ended data and it involves certain steps, such as coding or narrative analysis, to help organise the data (Creswell, 2009).

The next step was for the researcher to begin marking units of meaning, or themes. The coding process was inductive and codes were selected according to what they mean to the researcher. Codes which related to one another were grouped together or categorised. These codes were influenced by the data, by the theory behind the research and by the research questions. Building from this, Bryman (2004) suggests the following considerations about coding: coding as soon as possible, reading through everything first before starting work on coding; reviewing the codes and making sure there are no repetitions and that they all relate back to the research; beginning to

generate some theoretical ideas about the data and highlighting links and connections between themes and sub-themes.

This study used thematic content analysis to organise the transcripts into themes which were then discussed and applied to the literature. This method emphasises the organisation and rich description of data. (Attride-Sterling, 2001) notes that thematic content analysis aids in identifying the different themes emerging at different levels and the thematic network ease the structuring and description of these themes. The themes were then coded into categories, which were generated into themes according to the major findings. The themes were described into qualitative narratives and then made into an interpretation in qualitative research, which will be the final report (Creswell, 2014).

Coding was done to reduce the amount of data and encourages the researcher to begin thinking about meaning of the data. Creswell (2014, p. 198) states "codes on topics that readers would expect to find, based on the past literature and common sense; codes that are surprising and were not anticipated at the beginning of the study; codes that are unusual, and that are, in and of themselves, of conceptual interest to readers". Although there are a number of different ways codes can be done, for the purposes of this research, codes were developed according to the data collected during interviews and no predetermined codes were applied to the process.

Each theme developed had the potential to be used as a basis for an argument in the discussions which came later. The raw data, once organised thematically, still did not represent findings until the themes were discussed and arranged to support an argument which related back to the research question. It was used to develop descriptions of the people, the setting and the themes. The data was represented and discussed by using narrative passages, which conveyed the findings and arguments of the researcher. This interpretation used the researcher's own experiences as well as the information taken from the literature and theories in order to develop an analysis which was interesting, relevant and helpful in exploring the topic of this study (Creswell, 2014).

3.7 Trustworthiness of the study

To ensure the trustworthiness of this research, the researcher observed the principles of validity and reliability. Creswell (2014, p. 201) states, "qualitative validity means that researcher checks for the accuracy of the findings by employing certain procedures, while qualitative reliability indicates that the researcher's approach is consistent across different researchers and different projects".

A further four criteria were applied to ensure that the research is trustworthy. These are: credibility, transferability, triangulation, dependability and confirmability as alluded to by Krefting (1991). Credibility was ensured through the use of face to face interview with participants from an HCBC organisation, including literature from other HCBC studies.

Credibility refers to the commitment by the researcher to spend enough time in the field to ensure that recurrent themes and patterns can be identified (Krefting, 1991). Even though the researcher did not spend prolonged time in the field, the credibility of the study was ensured from a long-term working with the organisation and others rendering similar services.

Morrow (2005) describes transferability as the ability of the reader to generalise the findings of the study to their own context. The aim of this research was to explore the perceptions of a specific group of participants, located within a specific context and project. The assumption is therefore that this study is descriptive in nature, making transferability a non-issue (Krefting, 1991). According to Creswell (2009), it is the particularity rather than the generalisability of qualitative research which makes it so important. However, care has been taken to ensure that the research was carried out in such a way that the same methods could be used to research other case studies.

According to Krefting (1991, p. 216) transferability is the criterion against which applicability of qualitative data can be assessed, it is however more the responsibility of the person that wants to

transfer to another situation or population than that of the researcher of the original study. To ensure transferability the researcher provided a detailed description of the research methodology utilised; and care has been taken to ensure that the research was carried out in such a way that the same methods could be used to research other case studies.

Triangulation ensured that themes have been justified by examining them according to literature review and participant interviews. Description was used to convey the findings and allowed the reader to get a full understanding of the setting and create a feeling of shared experience. Negative information ensures that should there be contradicting themes or opinions, these too were touched upon in order to ensure that the account of the themes and findings are realistic and therefore valid (Creswell, 2014).

Dependability refers to the consistency of findings. For qualitative research this is more difficult to prove, however by describing the exact methods of data collection, analysis and interpretation, dependability has been enhanced (Krefting, 1991). Therefore, this report provides a thorough description of the research instruments, data collection and analysis methods used throughout the study. Creswell (2009) explains that reliability in quantitative research relates to dependability in qualitative research. A pre-test of the interview schedule also helped ensure accuracy of the research instrument.

Confirmability acknowledges that research is never objective (Morrow, 2005). It explains that results should reflect that which is being researched as far as possible, and not the thoughts or ideas of the researcher. The researcher is tasked with representing the data in a way that confirms to the reader that the findings are accurate (Morrow, 2005). Triangulation of sources helped to ensure confirmability of this study.

3.8 Ethical considerations

Ethics are the principles of conduct and behaviour that are considered morally correct and conform to the standards of the social work profession and all scientific researchers. Neuman (2014, p 145) states "the ethical issues are the concerns, dilemmas and conflicts that arise over the proper way to conduct research. Ethics define what is, or is not legitimate to do or what "moral" research procedure involves". The following ethical aspects were considered by the researcher during this study:

3.8.1 Voluntary participation

No participant was coerced to participate in this study. Strydom (2001) mentions that participation should at all times be voluntary and no one should be forced to participate in a project. The participants were informed during contracting and throughout the process that they are free to withdraw at any time they feel uncomfortable without any negative consequences, and that they will be referred for debriefed should the need arise. No participant were coerced to participate and no incentives were promised or provided. In fact, one participant decided to quit during the contracting session and there was no threat or intimidation towards her. One participant did not show up for the session, but it was later discovered that she had a court case to attend and maybe forgot to tender her apology. More information on voluntary participation was outlined to the participant information sheet, Appendix A, which was given to all of them.

3.8.2 Informed consent

The researcher ensured that informed consent forms an integral part of data collection. "The participants were informed regarding the nature and purpose of the study and their choice to participate or not" (Leedy & Ormrod, 2005, p. 101). Other information that the participants received was the aim of the research, the procedures that will be followed including permission to use tape recorder. "Participants can become aware of their rights and what they are getting involved in when they read and sign a statement giving informed consent, a written agreement to participate given by people after they have learned some basic details about the research

procedure (Neuman, 2014, p. 151). Informed consent as well as permission to tape-record the interviews were requested and received in writing (see Appendix B).

3.8.3 Avoidance of harm

Even though the researcher ensured that no harm of any nature, be it physical or emotional was done to the participants, it is worth mentioning that many emotions were aroused in the interviews. Leedy and Ormrod (2005, p. 104) suggests that the physical and emotional risks involved in a study should be no greater that risks of day-to-day living. The participants were made comfortable, given time to recollect themselves to ensure if they can proceed. Continuous reference was made for debriefing by the contracted social worker and Life Line as outlined in the participant information sheet, (see Appendix A).The participants were further reassured that their views will be representing all community caregivers in Tshwane Region, therefore none of them will be identified or associated with any quotation or statement in the final report.

3.8.4 Confidentiality

Every measure was taken to ensure that the all information is secured by locking the tapes and transcripts away and password protect the transcriptions on the computer system. "Confidentiality will also include the storage of both raw and processed data. Only the researcher, supervisor and translator (if needed) will have access to the tape-recordings and transcripts" Strydom (in De Vos et al, 2011, p. 120). The participants were reassured during the signing of the informed consents that no names will be published or revealed to anyone except the researcher's supervisor who is highly professional and trustworthy (see Appendix A).

3.8.5 Violation of privacy

In order to respect the participants' rights to self-determination, they were not forced to divulge information or aspects of their lives that they are not comfortable with. Strydom (in De Vos et al, 2011, p. 119) states that privacy means to keep to oneself that which is normally not intended for

others to observe or analyse. For this reason, no information will be made available to anyone to analyse or scrutinise except the academics working with the researcher. Information shared off the record were not be used in the report as requested by the participants and promised by the researcher.

3.8.6 Anonymity

Bless and Higson-Smith (2000) note that in anonymity the information should not be linked with a particular person, thus the names of the participants can be omitted altogether or participants can be identified by numbers instead of their names. To ensure anonymity the researcher use numbers to identify the participants. Participants were informed that their responses would remain anonymous and confidential and ultimately represent all the community caregivers in Tshwane Region. The managers were aware of participants who volunteered to participate in the study but they were informed that no feedback will be given to them and that only a summary of the report will be given to the organization after finalization of that study. Furthermore, no contact were made with them ever since the introduction and neither at the end of each session to ensure that the participants do not feel uncomfortable or intimidated.

3.8.7 Debriefing of participants

During the process of the research, some issues that can affect the participants negatively or emotionally can come to the fore. “Debriefing sessions after the study, during which subjects get the opportunity to work through their experiences and its aftermath, are one way in which researchers can assist subjects in minimising possible harm which may have been incurred in spite of all their precautions against it” (Strydom, 2011, p. 122). Therefore, any participant who needed debriefing was referred to a counsellor who was contracted in advance. Some participants might need the debriefing for reflection purposes, not necessarily that they have been traumatised but to clarify issues that came out and seeks more information regarding the whole process.

CHAPTER FOUR

PRESENTATION AND DISCUSSIONS OF FINDINGS

4.1 Introduction

This chapter presents the analysed data and outlines the findings against the objectives of the study. Thematic content analysis was used to analyse the demographic information as well as the views and perceptions of the participants. Direct quotations are used to give voice to the participants.

4.2 Demographic profile of the participants

Table 1 Profile of participants (N=14)

Demographic factor	Sub-category	No
Gender of caregiver	Male	3
	Female	11
Age of caregiver	21-30 years	6
	31- 40 years	3
	41- 50 years	4
	50- 60 years	1
Marital status	Single	7
	Married	5
	Divorced	1
	Widowed	1
Parental status	Mother	8

	Father	2
Level of education	Grade 9 -12	14
	Post matric	7
	Social Auxiliary work	1
	Child and youth Care Work	5
Years employed at the HCBC	0- 5 years	6
	6- 10 years	3
	10- 15 years	5
Home language	Setswana	2
	Sepedi	1
	isiNdebele	7
	isiZulu	1
	siSwati	2
	isiXhosa	1
Community setting	Urban	5
	Rural	5
	Peri-urban	4

In Table 1 the demographic profile of the 14 participants who are community caregivers in the three centres of the organisation in the Bronkhorstspruit area involved in the research study is presented. The majority of participants' home languages fall into either Nguni or Sotho. The interviews were transcribed in English.

The participants' ages ranged from 23 to 52 years. The variety of ages contributed to a fair share of experience and skills in the field of study, which is 2 to 13 years. There was also a good representation of gender among the community caregivers. The educational levels of the participants ranges from grade nine to grade twelve, 7 of them have done a course or two after grade 12 which include computer literacy, first aid, jewellery, a pastor and one was in the South African Army. Four participants are already qualified Child and Youth Care workers of whom two are already accredited and the other three have recently completed and are awaiting their accreditation, whereas one is accredited for Thogomelo programme. One participant is a qualified Social Auxiliary Worker but is working as a volunteer caregiver due to lack of job opportunity. Three of the participants are youth that were beneficiaries of the Orphaned and Vulnerable Children and Youth (OVCY) project in the same organisation.

4.3 Themes identified from the analysed data

Six main themes relating to the study objectives emerged during the interviews: motivation for becoming a community caregiver; Psychosocial challenges of community care work; impact of challenges on work performance; impact of challenges on home and personal life; assets, strengths and coping mechanisms and suggested interventions.

These themes were further divided into sub-themes, which were analysed with supporting extracts from the interviews and supporting literature that was reviewed prior to the study. These themes also addressed to the aim and objectives of the study.

Table 2 an overview of themes and sub-themes identified during analysis of data collected from community caregivers working in Home and Community Based Care Centres.

Theme	Sub-themes
1.Motivation for becoming a community caregiver	(i) Love for children and community work (ii) Unemployment

2. Psychosocial challenges of community care work	(i) Lack of resources (ii) Finances (iii) Lack of support
3. Impact of challenges on work performance	(i) Despondency (ii) Loss of zeal (iii) Pushing for statistics
4. Impact of challenges on home and personal life	(i) Neglect of own children (ii) Impact on marriage (iii) Inability to separate emotions
5. Assets, strengths and coping mechanisms	(i) Hope (ii) Love (iii) Faith in God (iv) Drinking (v) Art- music
6. Suggested interventions	(i) Toll-free help line (ii) Monthly debriefing sessions (iii) Working care for carers programme (iv) Full-time counsellors (v) Living wages

In Table 2 an overview of the themes and sub-themes that emerged during the interviews with the community caregivers. These themes will be explained and explored below.

4.3.1 Motivation for becoming a caregiver

The majority of participants mentioned that they started as volunteers who wanted to help children in need of care while others were recruited by the organisation to volunteer and assist in rendering the services to the children especially cooking and cleaning of the facility. When funds became available, the volunteers were considered to receive the stipends. Some of the caregivers were beneficiaries at the centre and as a form of after care service and focus on vulnerable youth out of school; they were called to work as caregivers at the centre. Others were merely looking for any job available and landed in the centres.

One of the participants mentioned, *"I was a beneficiary here at the centre while I was still attending school because I am an orphan. The manager called me saying there was a vacancy so I came to work. There was space for one but because we were two, me and the other girl that was just here now they took us both.* Participant no 13, *"I grew up as an orphan, my parents died when I was very young. Where we come from there were no such services for orphans. We came to live with our aunt here and that is how we came to be beneficiaries of the centre. I now live here at the centre as a caretaker of the premises."*

4.3.2 The psychosocial challenges of working as a caregiver.

Due to the high rates of unemployment in South Africa, more and more people resorted to volunteering with the hope to ultimately being employed. The availability of foreign and local donors as well as government intervention made it possible for the NPOs to pay a stipend to the volunteers. Notwithstanding the fact that home and community based care services are rendered by NGOs with no source of revenue, people perceive volunteering as a stepping stone to permanent employment.

The challenges faced by the caregivers range from a lack of resources, absence of support by management to low stipends that do not afford them to maintain their families.

For example, almost all participants mentioned lack of resources such as food parcels for the beneficiaries as a cause of demotivation in their work:

Participant no 9, *"Most of the times we find cases like those that are on treatment, they don't have food and we cannot provide them food parcels. So they become frustrated when we want them to sign the stats while we don't provide their needs."* Another participant shared *"Sometimes I used to take food from my house and of which I am not getting so much…. And I am a single parent. But it hurts me, but what is good is that my children understand, so whatever I have I just share with the needy-needy families at that time."*

The amount of stipend not being a living wage tempt some participants suggesting that food parcels from the nutritional meals meant for the beneficiaries (the children) to should be given to them as caregivers to supplement their basic stipend paid to them at the end of the month. One of the participants noted "*I was telling HR that, say we get enough groceries donated from Makro, why don't you motivate the staff by giving them some tin fish, cooking oil or something because we know that DSD is funding the nutrition for the children. We don't even get bonuses at the end of the year, so how are we motivated?"* Another participant had resentment and jealousy towards the CYCWs who were deployed from other organisations and placed at their centre, as it is an Isibindi site.

Participant no 6 highlighted *"The main challenge is the money, we get very little money. They never trained us; they took the Isibindi people from outside and brought them in. We were never trained. We get very little money. The R 1 800, 00 per month worries us a lot… After all these years we have children, we cannot do anything for our children, not that we can do everything, but this money is too little. We are always complaining about the money".*

The WHO (2002) states that HCBC should not be seen as a cheap alternative to medical care, and emphasises that volunteers (HCBCs) should be supported properly and recognised for the

work they do. However, despite the monetary support, the community caregivers deserve holistic psychosocial support pending on the intensity of the work they do.

REPSSI (2009, p. 44) states: "not only do they have to cope with the painful situation of their clients, but many of them are also living with HIV and going through the same situation as their clients. Or they themselves are grandparents taking care of orphans, having seen their own adult children pass away". Therefore, it is important to consider such circumstances, render the necessary support and training to such caregivers, in order to support and enable them to deliver effective services to their clients.

Participant no 5 mentioned, *"I have a 10 yrs old child and I'm not married. It is not enough money. My child goes to a school for children with learning difficulties. I pay R980, 00 for transport and school fees. There is no one working at home. I'm staying with my parents, my father is not working, and my mother is mentally disturbed and does not get a grant…"* The participant shared crucial psychosocial circumstances about herself. She has a child with learning disability also living with HIV/AIDS, a mother with mental health, herself also living with the disease and a survivor of sexual abuse. When she came to the organisation she was looking for help, getting the job was more of a blessing on the financial side however, she now does not receive any attention as she is considered staff member earning a stipend. Therefore her psychosocial needs are still unattended.

4.3.3 The impact of psychosocial challenges on work performance

DSD (2012) states that community caregivers work under stressful conditions that may lead to disillusionment and burnout. They need support to do their jobs well, remain infection free and avoid burnout to ensure that sustainability and quality of their services are not compromised.

This research has proven the opposite of what the framework stipulates. Almost all the community caregivers who participated in this study are very disillusioned, stressed or even depressed and are compromising the main purpose of home and community based care services.

The general feeling is that participants are only collecting signatures for purposes of submitting statistics to donors especially the DSD. They express loss of love for the work and developing fear of being thorough because it ends up ineffective and leaving the client exposed and more vulnerable.

Participant no 1 highlighted *"You become affected and scared of facing them again because you don't want to make empty promises again due to lack of resources."* Participant no 11 argued, *"They affect my performance because sometimes I feel that because I grew up not having food at home, depending on the project's meals, if I find a similar situation I can't come back to ask the same questions which I couldn't solve".* Participant no 13, *"We just do it for the sake of the report. When they need the report, you just have to submit" "So you want a signature- the family refuses. You get back, the manager wants stats"* Another participant compared the status to the previous conditions they used to work under *"It's not like before when you had the dignity of going to work. When you get here, your heart just feels down".* Participant no 1 complained, *"The homes are far apart from each other. You do not have enough time to sit and talk about everything. So others I just brush off and proceed".* This participant wondered, *"I ask myself, why do I register these families if I cannot assist them"*

In their endeavour to render quality services, community home based caregivers encounter problems and barriers which include structural problems, lack of resources, lack of transport money and very low stipends, supervisors' lack of management skills and not being welcome by patients and family members (Moetlo, Pengpid & Peltzer, 2011). The participants are disillusioned due to lack of support, supervision and resources. This renders them impatient and

incompetent in the execution of their duties. Ultimately, they are blamed ad ridiculed for failing to render effective services.

4.3.4 The impact of psychosocial challenges on home and personal lives

The psychosocial challenges affecting community caregivers at work translate directly into their homes and personal lives. One participant mentioned that she realised after her divorce that the husband must have been feeling rejected and neglected, hence the husband was drinking too much and always complaining about her work. Another one blames her noise and hostility at home for her child failing grade 12. She has developed high blood pressure due to forever being stressed up. She said she only realised after her mother's death that she was actually an alcoholic and had to stop, as she no longer had support or anyone to take care of her children, she was drinking every night. This participant mentioned, *"I am using this noise from here at home. You see I am now blaming myself for the 21 year old to fail matric because I do not give them the welcoming love at home. When I see my kids it's like I see my colleagues, I get emotional…on the 21st I went to the clinic they said my high blood was uncontrollable"*

Some of them feel even more depressed on payday when they cannot meet any household needs. *"I have four children; I must send them to tertiary. I take loans all over the place but I leave them all half way to help the other. Now none of them can find a job because they did not finish. I am still struggling to pay off the loans. Their father cannot work because he had an accident; he has a plate in his leg so he cannot work. I feel because of my age I can't get another job elsewhere so I just hold on"* "*I think the one person that was affected negatively was my husband… we ended up divorcing. When we argued, he would say because of your many children, you never have time for me"*

The male participants feel they are undermined by fellow men for doing women's work and failing to support their families. *"I resigned for the South African National Force Reservist because of my love for children… I had many chances of going back but as a performing artist I*

think my life is for working with children…From the family side you know this Isibindi work is not for males it becomes difficult for me when it comes to finances. Sometimes at home, they call you when you are busy with a serious case. Later you are told that you were busy with other people's children when yours needed you most"

One participant mentioned that all she does is cry, especially when alone at home, she cries herself to sleep and life goes on, however, she tries hard to avoid situations that touch her emotions at work. According to WHO (2002) providing volunteers are paid a stipend and receive psychosocial support and health care. Furthermore, besides the payment of stipends, honouring HCBC team members is another form of retention and motivation. In addition, HCBC team members might be supplied with T-shirts, uniforms, bags, umbrellas, badges, etc. and need to hear from the health officials at higher ranks that their work is recognized and valued. The more important element in retention is that members of the CHBC team feel valued for their work and supported by the community and by other units and levels of the health care system.

4.3.5 Assets, strengths and coping mechanisms

Despite all the challenges and frustrations that the community caregivers experience daily, the majority of them mentioned love for children, faith, hope and perseverance as motivating factors for staying at the organisation *"I love children. I always had an idea of leaving this place to open my own crèche. I actually did not want to have children of my own, I wanted to raise other children, but by God's blessings I have my own children"*.

Few mentioned that they feel that if they leave they will disappoint and abandon the children with whom they have developed rapport because they are their support systems. Very few confirmed family support as a reason to continue working as caregivers. This caregiver confirmed his family support where he talks about all his frustration and get comfort. *"I like talking, I have love and respect is number one".* One participant mentioned that she relies on divine strength to keep going *"I pray, I am a Christian so I get my strength from God".*

Some feel they have the potential to bring about change only if they are recognised and are given the opportunity especially the CYCW.

The participants did not indicate any recreational activities or leisure time, blaming it on lack of money and extreme exhaustions resulting in them only wanting to watch television or sleep. They do not see any value for taking vacation leave expect for family responsibilities. All the participants who were initially beneficiaries of the organisation mentioned that they wanted to come back as social workers to make a difference in the centre. They are still hoping for opportunities to come so that they can fulfil their dreams.

The responses of the participants in this theme confirm some of the principles of the Asset Based Community Development Approach. The caregivers are motivated by the love for their community and the need to assist orphaned and vulnerable children and their households. They go beyond the stipulated programme of the centre to teach more skills. *"I love children. I am a performing artist so I am always occupied with the children. We are sometimes called to perform at functions and wedding and they pay us so we buy attire. The love for art keeps me coming here".*

The participants displayed much love for their community, where most of them engage in extra mural activities just to give more back. They work overtime, after hours and even weekends and school holidays in order to engage in more activities which are exclusive to their daily routine at the centre. Such activities include and not limited to performing arts for entertainment and extra cash. This is indicates that there are assets in the community that need to be tapped into for the benefit of the entire community. These assets continue to impact the community by engage others who are not participating in the structured programmes. The further raise some funds for themselves to boost the stipends.

4.3.6 Suggested interventions

When exploring with caregivers their ideas on addressing the challenges they are experiencing in order to deliver better services to clients, most community caregivers mentioned that they are frustrated and have lost interest in the organisations. They acknowledged that they have the care for carers programme but it does not add value to their circumstances. Participant no 13 suggested, *"I would encourage support groups. All centres should have monthly support groups to have someone teach us how to deal with life issues"* Few of the reasons against the programme are that it happens at least once a year and they combine all the caregivers in the area. Therefore, they do not get the personal attention they desire. Another reason is that it is run by White people mainly Catholics, therefore they cannot relate to it and the activities do not talk to their challenges. This participant does not believe in imposed religious beliefs *"Their care for carers programme is based on the spiritual. Sometimes I do not need that thing. Maybe I need one-on-one session counselling*". At the end of the day nothing changes therefore, many caregivers do not even attend the programme when presented.

Most participants mentioned that they have limited or no access to their managers with regards to their challenges. Others say they would be reminded that they are there to work and not complain. "*Sometimes it does not even help talking to them because nothing ever happens to your request or suggestion"*. Some participants feel the community is not involved in the activities of the organisation and therefore have conflicting expectations. There is lack of communication between the organisation and the community. For instance, families were initially provided with food parcels, when the programme changed nobody informed them, therefore, they still expect food parcels when the caregivers conduct home visits. Many parents or caregivers of the OVC hardly attend annual general meetings hence they lack information. On the other hand, the management is not doing anything to encourage community participation. This participant believes if DSD could be directly involved their work would be easier. *"Is not DSD that is dealing with projects? I suggest if you can call the parents and explain how the project works. So that the families should know that if the caregivers cannot supply it's not their faults but there is a lack up there (paraphrased)."*

4.3.7 Support of community caregivers

From the analysed data, it is clear that support for caregivers is a major need. The payment of monthly stipends is just one form of support given to caregivers. *"So if you come with less than R2000, 00 put it on the table it's not easy. Therefore, if you are a married man- they say you must go and find a job. This thing is of yours is not working. I mean if you are working for R1600, 00 for a month, you definitely are told to go and look for a job."* DSD (2012, p. 34) suggest five components of support: "Social support, which includes peer support; emotional and psychological support, which includes general counselling; bereavement counselling, as well as related debriefing; supervision and mentorship; and debriefing sessions to relieve stressful situations". Financial strain contributes more to stress and depression. Hence, there are always complaints of poor performance, mediocre work and staff turnover. People, especially men feel inadequate when they cannot financially satisfy their family needs.

Lack of morale and motivation can interrupt family life. One participant lost her marriage due to neglecting her marital responsibilites due to work related stress and loss of focus on her immediate family*"I think one person that was negatively affected was maybe my husband. So I am divorced right now. We ended up divorcing".*

REPPSI (2009) suggests that with an explicit psychosocial support focus, the home and community based caregivers can start their own support groups, build support networks and focus on their own professional development to increase their competency. A well-structured and functional psychosocial support programme will increase competence, strength and independence. This participant is so overwhelmed with challenges that all she does is crying, almost every day "*No I don't talk, I cry at home".* She has no one to talk, has lost trust even in her available family.

4.4 CONCLUSION

It can thus be concluded that the psychosocial circumstances of community caregiver are affecting their work and personal lives negatively. It came out during the interviews that care givers are not given the necessary psychosocial support as required by WHO and DSD (2012). Most of them are sick and /or have sick family members but they are not given the necessary support, disregarding the fact that they were given the job as a form of intervention into their situation. They are in turn reminded that they are there to work or they are welcome to leave.

The interviews further exposed a fact that limited services are provided to the beneficiaries. The caregivers are focusing on getting signatures for the sake of statistics submitted to the DSD. Some participants mentioned that they have already lost trust and relationships with their clients and that raises the question of the sustainability of the HCBC services in the communities. This was confirmed by the following statement of one of the participants *"I don't want to get deeper with them so I just brush up, get the signature and move on."*

In addition, the disparity of the introduction of the Isibindi programme and bringing people from outside the organisation has also worsened the despondency. The caregivers struggle to believe that the child and youth care work system is a new phenomenon, which is growing and might accommodate most of them. The failure of management to explain how the programme works left people worried and jealous therefore loosing morale.

Therefore, it is concluded that the psychosocial circumstances of community caregiver working in Home and Community Based Care Centres are affecting their work and personal lives. They cry for support and resources to do their work better. The main findings final conclusions and recommendations will be presented in the final chapter.

CHAPTER FIVE

MAIN FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

This chapter concludes the study by presenting the main findings of the research, including the conclusions reached and recommendations for the improvement of policy and terms of good practice as well as implication for further research.

5.2 Main findings of the study

5.2.1 Objective 1: to explore the psychosocial circumstances of community caregivers

Most beneficiaries joined the organisation as volunteers hoping to get employed which ultimately happened. However, the stipends they receive do not allow them to meet their living needs. Some joined the system as they were also beneficiaries and getting involved was an alternative strategy for them to give back. In addition, one of the centres came across as having a vision to cater for the OVCY out of school by employing them to ensure that they continue benefitting from the services and not lost in space.

Very few participants have happy home and personal livelihoods with the challenges they encounter at work as additional contributing factors. For instance, one attributed her divorce to the working effects on her emotional wellbeing; one blames herself for her child's poor performance at school, while the other one feels socially undermined by community members for doing women's work, which cannot sustain his family. In addition, HIV/AIDS stigma is still very problematic among communities, families, health, and social welfare workers, hence male caregivers are ridiculed and undermined. Almost all the caregivers are emotionally overwhelmed, financially insecure and are barely coping. Some of them (the CYCW) had to cancel their child support grant (CSG) because they are earning more than R2 500, 00 which is the benchmark for social grants. However, the stipends they receive are not enough and the financial gap remains wide.

Literature review outlines that community caregivers also have personal circumstance, which are more or less the same as those of their clients. Repssi (2009, p. 44) states, "not only do they have to cope with the painful situation of their clients, but many of them are also living with HIV and going through the same situation as their clients. Or they themselves are grandparents taking care of orphans, having seen their own adult children pass away". This statement came out true to most participants and some of them feel indebted to the organisation because they are or used to benefit from the services.

5.2.2 Objective 2: To investigate the challenges that affect community caregivers and engage them in finding solutions.

The findings from this objective brought forth important facts regarding the psychosocial circumstances facing the community caregivers. The first concern in everybody's mind is the lack of resource due to the beneficiaries, which hampers them to deliver best services. The organisation initially provided food parcels to beneficiaries or households. This can be called a handout mentally or entitlement conditioning. Therefore, that perception remains in the minds of recipients of services and their main expectation is material and not necessarily psychosocial support. The inability to supply material goods harms the caregivers' morale and discourages them to continue rendering psychosocial support. The WHO (2002, p 64) concurs that the caring for ill people and family members at home presents many challenges. The CHBC team visits families that are destitute with no food, water, adequate shelter or access to necessary treatments. For this reason, many take the responsibility of providing material assistance upon themselves, even though they also do not have enough to sustain their own families. For instance, others mentioned that they usually share their family groceries with the beneficiaries or source some food parcels from the nutritional meals of the children at the centre.

The participants' backgrounds and circumstances are other factors affecting their work performance. These participants are infected and/or directly affected by HIV/AIDS. Most of

them are still living in the situation and have not had sufficient intervention to deal with their circumstances. For these reasons, many avoid similar situations in the field while the exposure and reminder of their backgrounds forever torture them. These circumstance compromise the vision and mission of HCBC and has little impact on the beneficiaries of the services.

Unemployment, poverty and lack of resources play a major role in the despondency of the caregivers. They are torn between crucial decisions: to leave or continue working. On the contrary, they are motivated by the love for the children and the willingness to remain assets in their community. They possess the necessary strengths and gifts such as empathy, sensitivity, non-judgmental attitude, confidentiality and motivation to serve the vulnerable groups and effect change in their lives.

The benefit of HCBC is that the caregivers bring relief and support on the family members by assisting them to physically and psychologically deal with the vulnerability. This gives the primary caregivers time off to take breaks or continue working if employed. They also help to see that the sick and vulnerable are neither neglected nor abused as they conduct home visits on regular basis. The care giving responsibility however, also renders the caregiver vulnerable to trauma and burnout. Hence, they also need psychosocial support.

The participants' most needed intervention is two-fold: psychosocial support and a living wage. A well-structured and monitored care for the carers programme will revitalise the love and voluntary participation accompanied by social cohesion and connectedness. The disparity of salaries for the qualified child and youth care workers versus the stipend received by volunteer caregivers should be addressed with utmost care and professionalism so that there is harmony and shared responsibility in terms of workload.

5.2.3 Objective 3: To probe the coping mechanisms that community caregivers apply in balancing their home and work circumstances.

Most participants complained of exhaustion and tiredness due to walking long distances conducting home visits against the elements of weather. One participant mentioned, *"We walk our shoes finished"*. In their endeavour to render quality services, community home based caregivers encounter problems and barriers which include structural problems, lack of resources, lack of transport money and very low stipends, supervisors' lack of management skills and not being welcome by patients and family members (Moetlo, Pengpid & Peltzer, 2011). Working with such barriers adds more strain to the caregivers the same way as the actual work itself. The caregivers carry and transfer their work stress to their families and subject their families to neglect. Some children have learned to adapt by taking over their parents' roles and standing in for them for instance carrying for beneficiaries when the parents are absent. Some children develop uncontrollable behaviour in reaction to lack of attention. Some marriages are suffering while others even break down. Those who lost loved ones do not receive grief and bereavement counselling as well as time to mourn, as they must continue working to earn a living. The conclusion in this regard is that the caregivers are barely coping in their work. They hardly have time for leisure and recreation.

5.2.4 Objective 4: to elicit suggestions from community caregivers about strategies needed to support them better.

REPSSI (2009) suggests that with an explicit psychosocial support focus, the home and community based caregivers can start their own support groups, build support networks and focus on their own professional development to increase their competency. A well-structured and functional psychosocial support programme will increase competence, strength and independence.

DSD (2012, p. 34) suggests five components of support. However, in this study, the participants mentioned that they have limited or no access to any of these components of support. They

receive little supervision or contact from their managers only during the collation of evidence to submit to DSD. Supervision does not only apply to the overseeing of the work done but also beneficial to the supervisee or case manager in this instance the caregiver. The caregivers have a desire to engage with their managers to share their frustrations, breakthroughs and just to get support and guidance.

5.3 Conclusions

In view of the research findings, it can be concluded that the psychosocial circumstances of community caregiver working in Tshwane Region affect their work performance, home and personal lives.

This study has exposed that the people entrusted with the psychosocial support of those affected and infected with HIV/AIDS and other chronic condition are just as vulnerable. They need more support to do their jobs better.

The study has also identified a gap in literature on the psychosocial support of community caregivers. There are policies in place, which also have gaps in terms of implementation, monitoring and evaluation.

Some caregivers, however, are benefiting from the service as it contributes to their development and afford those opportunities to improve their lives. These have been trained and accredited as Child and Youth Care Workers. They earn a living wage and have learned better skills to deal with work challenges. However, poor communication and withholding information from staff has led to other caregivers being disillusioned and jealous of those that have progressed, as they feel unfairly treated and discriminated against either due to their age or level of education.

Low stipends contribute to more dissatisfaction, as the caregivers cannot afford their living expenses while they are also vulnerable to the same conditions as their beneficiaries. This goes together with lack of support and supervision and being left to fend for themselves in services

rendering and acquiring resources. The available care for the carer's programme seems ineffective and least appreciated.

5.4 Recommendations

The following recommendations are made in terms of policy and future research. The custodians of policies and legal frameworks that address the psychosocial support of community caregivers' policies especially the Department of Social Development should see to the implementation, monitoring and evaluation thereof:

5.4.1 Monitoring and evaluation

With M&E systems in place, HCBC centres will remain an integral role player in the fight against HIV/AIDS and related chronic conditions.

5.4.2 Supervision and Training

Supervision and training are equally important in the support and competence of caregivers. It is essential that CCGs receive proper training to provide a high standard of care. A nurse or social welfare professional is usually responsible for supervision. The CHBC team should have adequate supervision and support from a person with the authority to make and carry out decisions. Such a person has to gain the respect of the CHBC team and the local community. In addition, this supervisor has to access available resources and advocate for CHBC funding. Education for CHBC supervision and management is therefore important (Cameron, 2003; WHO 2002).

Regular onsite visits, case audits, quality assurance and training by the DSD should form the basis of monitoring, evaluation and controlling of all the funded and unfunded NGOs rendering HCHC services.

5.4.3 Policies

There are many policies available on psychosocial support in its broad perspective and only need proper implementation, monitoring and valuation. There is also literature alluding to the care and support of community caregivers, "job description for CCGs; conditions of service of CCGs; financial policy; policy on confidentiality and disclosure; care policies, for example guidelines

for dealing with specific symptoms, and referral policy between different service components" Uys (2003).

5.4.4 Communication

Clear communication and training on these policies are essential so that all the caregivers, even the least educated can understand them to avoid conflicts and unfounded speculations. Communication is essential to both workers and recipients of services alike and improves the working relationship. This will yield the expected outcome of the intervention to both sides.

5.4.5 Research

The findings of this research indicate a great need and vacuum in the psychosocial support of community caregivers. This leaves room for research on the management and supporting structures in terms of how they plan to close the gap and the monitoring and evaluation of the psychosocial support services received by the community caregivers.

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APPENDIX A: ETHICS CLEARANCE

Research Office

HUMAN RESEARCH ETHICS COMMITTEE (NON-MEDICAL)
R14/49 Ntobeng

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER: H15/09/29**
PROJECT TITLE	The psychosocial circumstances of community caregivers: A case of Tshwane region
INVESTIGATOR(S)	Ms N Ntobeng
SCHOOL/DEPARTMENT	Human & Community Development/
DATE CONSIDERED	18 September 2015
DECISION OF THE COMMITTEE	Approved unconditionally
EXPIRY DATE	19 November 2018

DATE 20 November 2015 **CHAIRPERSON** J. Knight
(Professor J Knight)

cc: Supervisor : Dr E Pretorious

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10005, 10th Floor, Senate House, University.

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to completion of a yearly progress report.**

_____ _____/_____/_____
Signature **Date**

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES

SOCIAL WORK
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

Private Bag 3, Wits, 2050 • Tel: 011 717 4472 • Fax: 011 717 4473 • E-mail: socialwork.SHCD@wits.ac.za

APPENDIX B: PARTICPANT INFORMATION SHEET

THE PSYCHOSOCIAL CIRMCUMSTANCES OF COMMUNITY CARE GIVERS: A CASE OF TSHWANE REGION

Good day,

My name is Sophia Ntikane Ntobeng, and I am a postgraduate student registered for the degree MA in Social Work at the University of Witwatersrand. As part of the requirement for the degree, I am conducting research into the psychosocial circumstances of community caregivers in Tshwane region. It is envisaged that this information will enhance the social workers' understanding of the psychosocial circumstances of caregivers and help to improve the support services for caregivers as well as influence policy at the provincial and national level.

I therefore wish to invite you to participate in my study. Your participation is voluntary and refusal to participate will not be held against you in any way. If you agree to take part, I shall arrange to interview you at a time and place suitable for you. The interview will last approximately one hour. You may withdraw from the study at any time and you may refuse to answer any questions that you feel uncomfortable with answering.

With your permission, the interview will be tape-recorded. No one other than my supervisor will have access to the tapes. The tapes and interview schedules will be kept in a locked cabinet for two years following any publications or six years if no publication emanate from the study. Please be ensured that your name and personal details will be kept confidential and no identifying information will be included in the final research report.

As the interview will include sensitive issues, there is the possibility that you may experience some feelings of emotional distress. Should you therefore feel the need for supportive counselling following the interview, I have arranged for this service to be provided free of charge by the Department of Social Development Bronkhorstspruit. To make an appointment, please contact Social Worker Ms. Nonkululeko Nkosi on 013 932 9953. Alternatively you can contact Life Line toll free number on 0861 322 322.

Please contact me on 079 895 7227, email address Ntikane.Ntobeng@gauteng.gov.za or sn0798957227@gmail.com or my supervisor Dr. Edmarie Pretorius on 011 717 4476, email address Edmarie.Pretorius@wits.ac.za if you have any questions regarding the study. We shall answer them to the best of our ability. Should you wish to receive a summary of the results of the study; an abstract will be made available on request.

Thank you for taking the time to consider participating in the study.

Yours sincerely

Sophia Ntikane Ntobeng

MA Student in the field of Social Development

Department of Social Work

School of Human and Community Development

University of Witwatersrand

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APPENDIX C: CONSENT FORMS FOR PARTICIPATION IN THE STUDY

THE PSYCHOSOCIAL CIRCUMSTANCES OF COMMUNITY CAREGIVERS: A CASE OF TSHWANE REGION

I hereby consent to participate in the research project. The purpose and procedures of the study have been explained to me. I understand that my participation is voluntary and that I may refuse to answer any particular items or withdraw from the study at any time without any negative consequences. I understand that my responses shall be kept confidential.

Name of Participant: ……

Date: ……....

Signature: ……

CONSENT FORM FOR AUDIO-TAPING OF THE INTERVIEW

I hereby consent to tape-recording of the interview. I understand that my confidentiality will be maintained at all times and that the tapes will be destroyed two years after any publication arising from the study or six years after completion of the study if there is no publication.

Name: ……

Date: ……

Signature: ……..

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APPENDIX D: SEMI-STRUCTURED INTERVIEW SCHEDULE

THE PSYCHOSOCIAL CIRMCUMSTANCES OF COMMUNITY CARE GIVERS: A CASE OF TSHWANE REGION

Community caregivers

SECTION A

Demographic information

1. Age:
2. Gender:
3. Race:
4. Grade/ level of education:
5. Home language:

SECTION B

To explore the psychosocial circumstances of community caregivers

6. When did you become a community caregiver?
7. How did you become a community caregiver?
8. What are the challenges you face as a community caregiver?
9. How do these challenges affect your work performance?
10. How do these challenges affect your home and personal life?
11. How do you deal with these challenges?
12. What solutions would you give to avoid or better handle these challenges so as to deliver better services to clients?
13. What are the strengths/gifts you have that help you to continue being a community caregiver?
14. How do you supplement your salary to meet your household needs?
15. How do you spend your leisure time (Off days, weekends, holidays, leave days)?

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APPENDIX E: LETTER FROM KIDS CARE AND SUPPORT TRUST

THE PSYCHOSOCIAL CIRMCUMSTANCES OF COMMUNITY CARE GIVERS: A CASE OF TSHWANE REGION

Head Office
Postal Address
P.O Box 725 Bronkhorstspruit
South Africa 1020
Physical Address
2235 Mngomezulu Street Zithobeni 1024
Tel: 013 9370726 Fax: 013 9370736 Email: kids.cst@gmail.com
http//kidscaresupporttrust.wix.com/trust
NPO 030-736. PBO 930026795

Re: Request for research with our organisation.

Dear S. N. Ntobeng

Your request to conduct research in our organization for proposed topics has been granted, and wishes you well on your studies, any information you want from us please don't hesitate to call us.

Yours sincerely

King Petla

APPENDIX F: PERMISSION FROM DSD GAUTENG PROVINCE



GAUTENG PROVINCE

Enquiries: Ms Kabunakaki Komane
Tel: +27 (0) 11 355 7892
File no: 20017

Ms Sophia Ntikane Ntobeng

Dear Sophia Ntikane Ntobeng

RE: APPLICATION TO CONDUCT RESEARCH IN THE DEPARTMENT OF SOCIAL DEVELOPMENT

Thank you for your application to conduct research in the Gauteng Department of Social Development.

Your application on the research **"The psychosocial circumstances of community caregivers: A case of Tshwane Region"** has been considered and approved for support by the Department as it was found beneficial to the Department's vision and mission. The approval is subject to the Departmental terms and conditions as endorsed by you on the 18/05/2015.

May I take this opportunity to wish you well in the journey that you are about to embark upon.

We are looking forward to a value adding research and a fruitful co-operation.

With thanks.

Dr S. Mokoena
Director: Research & Policy co-ordination
Date: 29/09/2015