

**THE PSYCHOLOGICAL IMPACT OF CAREGIVING ON CARERS OF HIV/AIDS
ORPHANS**

By

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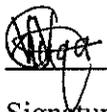
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DECLARATION

I, Valencia Veliswa Guqa, declare that *“The Psychological Impact of Caregiving on Carers of HIV/AIDS Orphans”* is my own work and that all sources that I have used or quoted have been indicated and acknowledged by means of a complete list of references.



Signature

2012-02-29

Date

DEDICATION

This thesis is dedicated to the memory of two phenomenal women:

- My mother **Rose Nompuku Guqa**. Mother and caregiver to the **Khanyiselani** orphans and other vulnerable children who passed away in 2008. No words can ever explain my love for you. Thank you for being a mother to me and raising me to be the woman I am.
- Ms **Theodora Makhalima**. Founder of Khanyiselani and mother and pillar to all caregivers and children of Khanyiselani who passed away in November 2010. My greatest sympathy goes to the loved ones left behind. May your soul rest in peace.

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ABSTRACT

HIV/AIDS epidemic has caused much devastation and has left many children destitute and in need of care and supervision. The present study investigated the psychological impact of caring on non-professional caregivers of HIV/AIDS orphans and children affected by HIV/AIDS. General systems theory stands as the epistemological framework informing the study. The study made use of a qualitative phenomenological approach to explore the lived experiences of eight non-professional caregivers who participated in the study. From the themes that were abstracted it was evident that caring for HIV/AIDS orphans is emotionally, physically and mentally strenuous for the caregivers. It was better recommended that caregivers be given recognition for their challenging work and be included in the planning and development of programmes that affect their caregiving role. Furthermore emotional, psycho-social, and income-generating skills support programmes including training and educational programmes should be implemented. This will alleviate the distress inherent to the caregiving role and to equip them with the necessary skills for handling the demands of their work.

CHAPTER 1

CREATING CONTEXT

1.1 Introduction

It has been over two decades since the outbreak of the HIV and AIDS pandemic, which has devastated families and communities. The rapid spread of the disease has resulted in families being separated from their loved ones. In 2001 it was estimated that 29 500 000 adults and children were infected by the Human Immunodeficiency Virus (HIV) globally. At this time sub-Saharan Africa accounted for about 20 400 000 HIV infections, while South Africa alone had 4 700 000 infections (UNAIDS & WHO, 2008).

According to Cluver and Gardner (2007) by 2005 there were approximately 830 000 maternal or double orphans in South Africa as a result of HIV/AIDS, an increase from 400 000 in the year 2001. As a result of the rising number of AIDS deaths in the years from 2001 to 2007 (increasing from 130 000 - 250 000 deaths in 2001 to 270 000 - 420 000 deaths in 2007) the number of AIDS orphans had increased to an alarming 1 400 000 in 2007 (UNAIDS & WHO, 2008).

According to Parikh et al. (2007) AIDS related mortality continues to be high and, irrespective of the expansion of the antiretroviral programmes available, the impact of orphanhood is likely to be dramatic in the years to come. The statistics presented above clearly illustrated the need for caregivers in the HIV/AIDS context. The present study focused on the experiences and perceptions of informal caregivers caring for HIV and AIDS orphans.

Caregivers play a vital role in providing for the psycho-social and emotional needs of HIV/AIDS orphans. These caregivers need to care for, support and protect AIDS orphans from risks and problems they encounter as a result of the pandemic. Provision of adequate care is essential to ensuring optimal growth and success in the lives of the AIDS orphans.

1.2 Problem Statement

Against a backdrop of rising adult mortality, a large number of children are becoming orphaned. The traditional extended family networks have been weakened and this has resulted in the development of an alternative social security system of caregivers. These caregivers include neighbours, community members, surviving aunts and uncles, and professional and non-professional caregivers (Foster, 2000). According to Bennett, Ross & Kelaher (1993, cited in Van Dyk, 2005) and Bellani et al., (1996, cited in Van Dyk, 2005) stress manifests more sharply and strongly in the HIV/AIDS field than in other fields. Continued exposure to the sickness and deaths of HIV/AIDS patients, the difficulties faced by AIDS orphans and children made affected by HIV and AIDS, as well as the financial difficulties reported by caregivers of AIDS orphans (Heymann & Kidman, 2008) further exacerbate the risk of occupational stress for AIDS caregivers.

HIV/AIDS caregivers also face stigmatisation and discrimination. They are often avoided and ostracised by community members, friends, family and colleagues because of the care they provide for people affected by AIDS (Van Dyk, 2005). This discrimination and isolation may result in a reduction in the quality of work rendered by caregivers. Other factors that may aggravate stress in caregivers and impact on caregivers' abilities and general feelings of well-being include over-involvement with those affected by the disease, the overwhelming effect

the epidemic has on children (Van Dyk, 2005) and the financial difficulties affecting the poor households affected by HIV/AIDS (Heymann & Kidman, 2008).

According to McCausland and Pakenham (2003) it is also possible for caregivers to experience enhanced appreciation of life and their existing relationships if they can adjust to the caregiving situation. Having resources to cope within their working situations enhances caregivers' experiences and they become more appreciative of their patients and of their own lives as a whole. These caregivers are then able to develop coping strategies that enable them to cope with working in their caregiving environments.

Caregivers in the AIDS field experience a lot of stress and distress associated with the HIV/AIDS epidemic. The problems and risks faced by the HIV/AIDS orphans in their care have an impact on the caregiving role. These problems and risk factors include emotional difficulties, shortage of economic resources, educational deprivation, stigmatisation, and depleted family structures.

In addition if children and adolescents are to survive and thrive they need to be raised in family and community environments that provide for their changing needs, thereby promoting their healthy and sound development (UNAIDS, UNICEF & USAID, 2004). According to the scale of human needs all children have physical, emotional, social and intellectual needs that must be met if they are to enjoy life, develop their full potential and become participating, contributing adults (Max-Neef, 1991). Caregivers of HIV/AIDS orphans have to be aware of the vulnerabilities faced by these orphans in order to be able to cater for their needs and provide them with protection.

Within the HIV/AIDS field caregiving does not occur in isolation, instead it occurs in a context that involves the caregiver, the child orphaned by HIV/ AIDS and the environment. Many caregivers of HIV/AIDS infected patients are professional caregivers such as nurses, health workers, doctors and social workers. Despite the dedicated efforts of these professional caregivers, they are not able to assist all HIV/AIDS orphans. The HIV/AIDS pandemic has resulted in the weakening of traditional extended family networks, and this has led to numerous non-professional caregivers taking on the responsibility of caring for AIDS orphans. This studied aimed to bring out the silent voices of non-professional caregivers in the field of HIV and AIDS.

1.3 The Purpose and Motivation for the Study

A large body of research exists concerning the role and experiences of formal caregivers (e.g. doctors, nurses, volunteers) within the context of the HIV/AIDS pandemic (Gueritault-Chalvin, Demi, Kalichman, & Peterson, 2000; Miller, 1995; Smit, 2005; Van Dyk, 2007). There has also been a vast amount of research conducted concerning the impact of HIV/AIDS on AIDS orphans and other children affected by HIV and AIDS.

This study sought to address the gap in the body of knowledge in the field of HIV/AIDS by exploring the psychological well-being of the informal caregivers of HIV and AIDS orphans and other children made vulnerable by HIV/AIDS. In addition, the study also looked at the caregivers' motivation for caregiving in the HIV/AIDS context.

1.4 Aims and Objectives of the study

The main aim of the study was to explore the psychological impact of providing care to children that are orphaned by HIV/AIDS. The study also aimed to make suggestions and inform interventions that will ultimately contribute to the caregivers' well-being. Finally, the study aimed to highlight ways in which these caregivers can better cope with the difficult task of caring for HIV/AIDS orphans and other children affected by the HIV/AIDS pandemic. In order to investigate the psychological impact of providing care for HIV/AIDS orphans, the following specific research objectives were outlined:

- Investigate levels of support among caregivers working with children orphaned by HIV/AIDS;
- Explore how caregivers manage the levels of stress typically associated with caregiving within the context of HIV/AIDS; and
- Investigate the nature of social and professional relationships associated with caregiving within the context of caring for children orphaned by HIV.

1.5 Research Questions

Based on the above objectives the following specific research questions were formulated:

- What are the lived experiences of caregivers working in the context of HIV/AIDS?
- What motivates the caregivers to take care of children orphaned by HIV/AIDS?

1.6 Research Methodology

In order to achieve the aims of this study a phenomenological research approach was adopted. This research approach was deemed appropriate as the study investigated the lived experiences expressed by the participants. According to Lester (1999) phenomenological approaches are based in a paradigm of personal knowledge and subjectivity and emphasise the importance of personal perspective and interpretation. These approaches therefore provide powerful tools for understanding subjective experience, gaining insights into people's motivations and actions, and cutting through the clutter of taken-for-granted assumptions and conventional wisdom.

Making use of a phenomenological based approach locates this study within the paradigm of qualitative research. This research paradigm was deemed appropriate to the purposes of the study as the aim of the study was to investigate the participants' perceptions of caregiving in the HIV/AIDS context. The participants' reality is thus based on their lived experiences. The data for this study was gathered through the use of interviews using a semi-structured questionnaire.

1.7 Structure of the study

Chapter 2 focuses on caregivers of AIDS orphans experience of stress. It also discusses the transactional stress and coping model from within a general systems theory perspective. This chapter also provides an overview of the support systems available to caregivers of HIV/AIDS orphans. Finally, the chapter discusses problem focused coping strategies and the emotional coping strategies model.

Chapter 3 discusses the methodology of the study, with specific focus on questionnaire design as a tool for assessing the psychological impact on caregivers of caring for AIDS orphans and other vulnerable children.

Chapter 4 presents the themes that transpired from the participants discussions.

Chapter 5 provides a discussion and analysis of the research findings.

Chapter 6 summarises the theoretical framework of the study as well as the findings of the empirical evidence obtained in the research. This final chapter also provides recommendations, suggestions and conclusions regarding effective practises to help support and enhance caregivers' well-being.

CHAPTER 2

CONCEPTUAL FRAMEWORK

2.1. Introduction

The earliest cases of AIDS in South Africa and Africa were reported in 1982 amongst homosexual men. In the early 1990s the virus became more prominent in the heterosexual community and South Africa was identified as having one of the highest HIV infection rates in the world (Armstrong, 2000).

This study focused on the caregivers in Kokstad, an area in the KwaZulu-Natal province of South Africa. KwaZulu-Natal (KZN) has the highest prevalence of HIV/AIDS of all South African provinces. Unemployment and income poverty are also much higher in KZN than the national average. HIV prevalence in the province is heavily concentrated amongst working age Africans. Statistics suggest that HIV is most prevalent amongst females aged 20 to 30 years old and slightly older males of 35 to 49 years (Armstrong, 2000).

Kokstad is an urban area on the border of KwaZulu-Natal and the Eastern Cape. The population in this area differs widely in their socio-economic and demographic characteristics. The Kokstad community includes the 'poorest of the poor', the 'just managing to get by', and the rich (National Department of Health & Social Development, 2005). Khanyiselani, the organization that was the focus of this study, was selected as one of the seven pilot sites in KZN for the implementation of the "National Integrated Plan for Children and Youth infected and affected by HIV/AIDS".

In order to place the impact of caregiving in context this research study made use of the theoretical framework of General Systems Theory. This theoretical framework is discussed below.

2.2. Theoretical overview

The General Systems Theory was proposed in the 1940's by the biologist Ludwig von Bertalanffy (Heylighen & Joslyn, 1992). Systems theory is described as general because it takes into account numerous mutually interacting systems. It also seeks to gain a holistic view of a phenomenon (Covington, 1998). At its most basic level General Systems Theory can be defined as elements that are in exchange and that are bounded. These components constitute a system, which functions or operates within a field or an environment. Elements can be virtually anything; in this case the elements are the caregivers and the clients. Exchanges are any relationships that exist between elements and the boundary refers to the things that are seen, felt, heard or sensed that separate the system from the environment Gregory (2011).

The boundaries of a system may be permeable or impermeable, thus making the system either open or closed Gregory (2011). The concept of openness or closedness is one of the fundamental concepts of systems theory. A system must be open to changes in its environment if it is to stay vital, active, and relevant. Changes in the environment result in the system changing in some way to order to adapt to the new realities (Covington, 1998).

In the context of this study the Khanyiselani organisation can be seen as a system existing within the larger context of the HIV/AIDS pandemic. It is an open system that permits

working relationships amongst caregivers and patients and is characterised by an interchange of behaviour and emotions. There is also constant interaction with other outside structures or organisations such as schools for the children, interaction and feedback from the community regarding the services, and support for caregivers by keeping them informed and educated regarding their role as caregivers thus transferring skills to ensure sustainability and continuation of service delivery.

In addition to looking at systems in general, systems theory also focuses on people and their interactions within other systems Gregory (2011). These other systems are known as the sub-system (group), system (community) and supra-system (managers and organisations). Thus, the caregivers of HIV/AIDS orphans should not only be observed in relation to their interactions with the orphans and their families. Instead, their interactions as a group of volunteers with some common purpose or goal within their community should also be noted. The community's involvement in their work could ensure a sense of belonging and partnership in their project. In addition, the caregivers' relations with their superiors and the external structures they are in contact with, such as hospitals and social departments, also need to be noted. The psychological well-being of the caregivers is therefore affected by their relations with their patients and by the broader systems in which they exist.

Based on the above discussion of General Systems Theory and in accordance with statements made by The Commission on HIV/AIDS and Governance in Africa (CHG) (2005) it is clear that caregiving in the HIV/AIDS context should not be viewed as an isolated condition. Instead, HIV/AIDS exists within a wider socioeconomic context that deepens the vulnerability of households, communities and nations. HIV/AIDS exacerbates and is

exacerbated by prevailing economic conditions.

The presence of HIV/AIDS in a household quickly results in the depletion of household income earning capacity and of household savings and assets. Many households quickly move into conditions of poverty, characterised by very little income or wealth, reduced access to services, debt, and fewer options for attaining socioeconomic security (CHG, 2005). This was further demonstrated in a published report of 2002 containing an overview of HIV/AIDS in South Africa (Gilbert & Walker, 2002). The report from the commercial sector expressed the magnitude of the impact of the epidemic in various levels, including high levels of absenteeism and ill-health in the workplace; large number of AIDS orphans placing a serious burden on welfare and health agencies; existing health care facilities struggling to cope with the treatment of AIDS related conditions; and government's unwillingness to provide effective treatment to all HIV patients.

According to Pearlin (1980) people's emotional states are impacted by a variety of elements, including larger societal and organizational structures. Pearlin (1980) stated that societies and their organisations are the source of forces that have the capacity to adversely (and beneficially) impact the well-being of people. The next section therefore looks at caregivers in the context of HIV/AIDS and examines the consequences they experience as a result of providing physical and psychological care to others.

2.3. Caregivers of HIV/AIDS orphans

Even as new treatments transform HIV infection from a terminal to a chronic illness, the social, economic and emotional consequences of a

potentially catastrophic disease reverberate within families of those infected. Nowhere is this more evident than where a child's mother dies or is too ill to serve as a primary caregiver (Joslin & Harrison, 2002).

Most HIV and AIDS orphans are cared for by members of their own family. These family members include the surviving parent, grandparents, other adults and brothers or sisters (Aids alliance, 2007). However, traditional family networks for caring are being weakened as a result of the epidemic (Foster, 2000) and thus the role of caring has been extended beyond the family to neighbours, non-relatives and community members. These individuals are referred to in this study as informal caregivers. This study focused on informal caregivers of HIV/AIDS orphans and other children affected by HIV/AIDS. According to McCausland and Pakenham (2003), informal caregivers play a vital role in community-based care within the HIV/AIDS field. Approximately 90% of this community based care is provided by women and girls (UNAIDS, 2006).

Much of the research concerning the role of caregivers has focused specifically on professional caregivers of HIV/AIDS patients (Bennett, et al., 1993; Bennett, Ross, & Sunderland, 1996; Dorz, Novara, Sica, & Sanavio, 2003; Gueritault-Chalvin, et al., 2000) or on primary caregivers such as grandparents, surviving parents, siblings and other family members (Caliandro & Hughes, 1998; Joslin & Harrison, 2002; Oburu, 2005). Very little research has focused on informal caregivers. This study therefore aimed to address this gap in the literature.

Within the context of this study it is important to note that although the focus is on caregivers of HIV/AIDS orphans and children affected by HIV/AIDS, these caregivers do not work with these children in isolation. In many cases, the caregiver is also responsible for the surviving ill parent or other guardian of the AIDS orphan(s). In addition, in the context of HIV and AIDS caregivers, whether professional or informal, provide a range of assistance across the disease continuum including medical assistance and nursing care, personal care, social support, emotional support, assistance with financial and legal matters and assisting with or providing transportation (Joubert, 2005; UNAIDS 2008).

In their study of caregivers of children affected by HIV/AIDS Caliendo and Hughes (1998) noted that some of the children are also HIV infected. These children thus require special health and often have mental health needs. In addition, most individuals who provide care are unpaid and poor and the additional financial and emotional report burden of administering care frequently pushes them into destitution (UNAIDS, 2000). Other research studies suggest that caregivers often report becoming too involved with their patients. As a result when a patient's condition deteriorates the sense of loss and the impact on the caregiver may be great (Bennett et al., 1996). The following section looks at the caregivers of Aids orphans and the impact of caregiving thereof.

2.3.1. Gender perspectives on caring and caregiving.

In the HIV/AIDS field the burden of care is carried mainly by women and girls (CHG, 2005; UNAIDS 2006; UNAIDS, 2008). Nyambedha, Wandibba and Aagaard-Hansen (2003) reported that in some sub-Saharan countries the absence of elaborate state based social

institutions to care for the constantly increasing number of orphans, prevailing poverty, and weakened familial support structures predispose most of the orphans and other vulnerable children to staying with their elderly grandmothers or living alone in their parents' homes. However, the Commission on HIV/AIDS and Governance in Africa (CHG) (2005) warned that the impact of HIV/AIDS on boys and men should not be minimized. According to UNAIDS (2008) a lesser but not insignificant number of men do provide care in the home and volunteer in home-based care programmes. However, UNAIDS (2008) also noted that economic, social and cultural patterns place males in more favorable positions to cope with the impact of HIV/AIDS.

When women assume the caregiving role they may have to give up jobs and income earning in order to care for a sick spouse or family member. Due to the demands of caring for others many female caregivers have less time to earn an income, produce food, go to school, and maintain the rest of the household. This creates a vicious cycle in which women and their families are more likely to be malnourished, in poor health, or economically destitute (UNAIDS, 2006).

The HIV/AIDS crisis has resulted in many grandmothers taking on the caregiving responsibilities of caring for their grandchildren as a result of rapid and dramatic changes due to the epidemic (Oburu, 2005). Older caregivers face significant challenges as they are often at a point in their lives where they expect to be cared for by their own children and are therefore physically, emotionally and financially unprepared to fully provide for their new dependants (UNAIDS 2008).

Research by Nyambedha et al. (2003) and Hunter and Williamson (2000) found that these grandmothers may be overwhelmed by the additional caregiving responsibilities and distressed by the deaths in their own families. Their ability to support their orphaned grandchildren is further limited by their advanced age, lack of assistance from relatives, and losses of income and personal freedom following the deaths of their own children. According to Jones and Hansen (1996) factors such as caregiver advanced age, elevated levels of experienced stress and poverty have been associated with caregivers' inability to provide the type of stable and consistent family environments necessary for positive child adjustment.

A smaller percentage of the care burden (Armstrong, 2000; UNAIDS, 2006; UNAIDS, 2008) falls on children, although this is often not acknowledged within the home environment (Armstrong, 2000). Many children who assume the role of household heads have little option but to seek work to support themselves and their siblings. Girls rather than boys tend to withdraw from schooling to assist with caregiving, household chores and family income support (CHG, 2005), thereby disrupting not only their education but also their future earning potential (UNAIDS 2008).

Armstrong (2000) described volunteers in the field of HIV/AIDS as the backbones of care in the community programmes. These caregivers step in to care for those infected and affected by HIV/AIDS. Their actions are usually motivated by a sense of love or duty, or a combination of both. In a similar manner to other caregivers in the field of HIV/AIDS, community volunteers provide a wide range of services, often combining both care and prevention. These caregivers have to sacrifice or manage competing demands related to their households' needs such as food, time with their families especially school going children who

still need guidance, and their own personal businesses (UNAIDS 2008).

The following section thus discusses the problems and risks faced by HIV/AIDS orphans and other children affected by HIV/AIDS. It also discusses the needs of HIV/AIDS orphans as well as the subsequent impact of caregiving in a context thus characterised by various challenges.

2.4. Problems and risks faced by AIDS orphans

HIV/AIDS threatens AIDS orphans' safety, well-being and development (Subbarao & Coury, 2004). After losing their parent(s) to HIV/AIDS, AIDS orphans and other children affected by HIV/AIDS have a great need for stability, care, and protection. The following sub-sections look at the various ways in which HIV/AIDS impacts on orphans.

2.4.1 Emotional impact

Children are affected by HIV/AIDS before they are orphaned. When a parent develops HIV related symptoms children often shoulder new responsibilities. These responsibilities include domestic chores such as cooking, cleaning, carrying water and doing laundry. New responsibilities also include caregiving activities such as feeding, bathing, toileting, giving medication and accompanying relatives for treatment, agricultural or income generating activities and childcare duties (Foster & Williamson, 2000).

As a result of these added responsibilities AIDS orphans and children affected by HIV/AIDS may suffer from psychological distress, showing common signs such as anxiety, depression, and anger (Avert, 2007). Stigmatization, increased workload, discrimination and social

isolation of AIDS orphans also increase the stress and trauma that occurs as a result of parental death (Foster & Williamson, 2000). It is therefore important for caregivers to be aware of these vulnerabilities in AIDS orphans.

2.4.2 Economic impact

In communities devastated by HIV/AIDS families are increasingly unable to provide the basic financial necessities and caregiving time children need for healthy development (Heymann & Kidman, 2008). Lack of access to basic necessities such as shelter, food, clothing, health benefits and education can have serious consequences for the child's survival when they have lost a parent(s) to HIV and AIDS (Avert, 2007). As a result of their loss many AIDS orphans depend on surviving family members for financial support to allow them access to these necessities.

AIDS mortality results in the addition of people to the surviving members' households. This leads to financial resources being strained and extra pressure being put on the orphans to contribute financially to the household. In some cases HIV/AIDS orphans are driven to the streets to work, beg or seek food in order to contribute to the household (Subbarao & Coury, 2004). As a result of these circumstances the child's needs for vital growth, freedom, and interaction are denied.

2.4.3 Education

The AIDS epidemic has resulted in children generally being less educated in the most heavily affected countries. This potentially diminishes the national capacity to accumulate human capital for future growth, prosperity, and development (Birdsall, cited in UNAID 2008).

Many caregivers of AIDS orphans cannot afford school fees and school uniform expenses (Avert, 2007). Dropping out of school and absenteeism are therefore both common among HIV/AIDS orphans.

In some circumstances HIV/AIDS orphans become heads of households. These children help supplement family income and take care of the ill (Coombe, 2000). These circumstances result in HIV/AIDS orphans and other children made vulnerable by HIV/AIDS being at risk of losing out on valuable life-skills and practical knowledge necessary for survival.

2.4.4 Stigmatisation

The AIDS epidemic has been characterised by severe negative public reactions including banning entry of HIV infected individuals, isolating an infected individual within the family, removing a person from his job, and even denying a child admission to school (Mawar, Sahay, Pandit & Mahajan, 2005). Society often stigmatises AIDS orphans grieving for dying or dead parents by associating them with AIDS. Despite the high prevalence of AIDS the disease remains surrounded by silence. People are ashamed to speak about being infected and many individuals view it as a scandal when it one of their family members is infected. People living with AIDS are exposed to prejudice born out of ignorance and fear on a daily basis. Individuals who are open about their HIV status frequently have no support structures (Udidi Consortium, 2005).

People who are affected by HIV and AIDS are often faced with shame, fear and rejection from the people around them. AIDS orphans are also therefore also likely to face discrimination if it is assumed that they are also HIV positive (Avert, 2007). As a result of this discrimination AIDS orphans often exhibit internalised behaviour changes such as

depression, anxiety and low self-esteem (Foster & Williamson, 2000).

2.4.5 Family structures

Freeman and Nkomo (2006) characterised the extended family in Africa as the traditional African social security system where members protect the vulnerable, care for the poor and sick and transmit traditional social values and education. In many communities affected by AIDS the mechanisms that keep families and households from destitution consist of material relief, labour, and emotional support from community members. People living in communities overburdened by AIDS recognise this principle of community support, with some community members volunteering their time and skills to care for orphaned children (Foster & Williamson, 2000).

In rural communities where traditional values are maintained the extended family safety net is usually fairly well preserved. However, in countries that are more urbanised extended family safety nets are weakened (Foster & Williamson, 2000). In addition, in many countries in sub-Saharan Africa where many people live below the poverty line additional pressure on the family substantially strains the family's financial, social and emotional resources (Freeman & Nkomo, 2006; Foster, 2000).

Within extended family systems the surviving family member also often have to cope with the alarming loss of their own support as a result of HIV, thus further eroding personal resources to absorb and care for family members (Freeman & Nkomo, 2006). As a result of these factors and the increasing number of orphans needing care and support, the traditional safety nets are inevitably being weakened (Foster, 2000).

2.5 The needs of AIDS orphans

In order to survive and thrive children and adolescents need to grow up in family and community environments that provide for their changing needs, thereby promoting their healthy and sound development (UNAIDS, UNICEF & USAID, 2004). The scale of human needs states that all children have physical, emotional, social and intellectual needs that must be met if they are to enjoy life, develop their full potential and become participating, contributing adults (Max-Neef, 1991). A brief account of the needs is provided below.

- Subsistence needs refer to the basic survival needs and include needs such as food, water and shelter.
- Protection needs involve the provision of basic health, psychological and social safety and also involve providing an infrastructure of protection against disease, sickness, violence, and abuse. In relation to these needs caregivers must continue to provide AIDS orphans and other vulnerable children with a sense of belonging and social and emotional support.
- Affection needs relate to parental and family love, emotional nurturing, intimate relationships with others, including friends and peer support. The provision of affection enables AIDS orphans and other vulnerable children to feel safe and loved. In the case where a parent has died, caregivers need to be able to talk to the affected children about the loss of their parent(s) (UNAIDS, UNICEF & USAID, 2004).
- The need for understanding relates to a child's need to develop the capacity for curiosity, intuition and critical thinking. It also relates to a child being able to develop an understanding of how he or she fits into the world in general. School attendance is

essential in satisfying this need. Education provides children with life skills and problem solving skills that can be used for future opportunistic goals and for survival (UNAIDS, UNICEF & USAID, 2004).

- Participation relates to the need to interact with families, friends, communities, schools, churches and colleagues. Having a loving family life and group activities with siblings and friends is important for the healthy development of AIDS orphans and other vulnerable children. These children need to experience a sense of security and belonging in a family or family-like environment (UNAIDS, UNICEF & USAID, 2004).
- Leisure needs relate to opportunities to relax, rest and indulge in hobbies or interests, or to spend time alone. Caregivers need to create environments where the orphans are able to participate in activities that provide them enjoyment as well as the opportunity to learn. Orphans should be free of the burden of responsibilities such as working at a young age. Instead, they should be able to develop positive self-identities and self-esteem through play and interaction.
- Identity refers to the sense of which one is; it is the value one places on oneself. This involves having self-esteem and experiencing a sense of worth within families, communities and peer groups.
- Creation needs refer to an ability to be productive and to having the capacity and skills to be a creative individual.
- Freedom needs relate to the right of choice and independence. Freedom is important on physical, emotional and social levels. HIV/AIDS orphans have the right to be protected from sexual abuse and exploitation, and the right to strive towards achievement of overall healthy and productive development (UNAIDS, UNICEF & USAID, 2004).

- Transcendence needs relate to the need for spiritual awareness and connectedness. Transcendence can be beneficial to AIDS orphans by allowing them to talk about the death and loss of parent(s), and allowing them to participate in rituals related to the person they have lost (UNAIDS, UNICEF & USAID, 2004).

This list of needs makes it clear that HIV/AIDS orphans require large amounts of protection, affection, and support necessary in order to survive and live optimal lives. Caregivers thus play an important role in the lives and survival of the AIDS orphans and other vulnerable children. These caregivers need to be parental figures, protectors, and providers for the orphans and other vulnerable children.

Caring for the children of extended family and neighbours often leads to increased anxiety and worry. The added responsibility of caregiving also further exacerbates poverty, as there are more mouths to feed. Caregiving also places numerous additional demands on the caregivers, and this can result in social isolation (UNAIDS 2008).

This research sought to understand aspects of the psychological well-being of caregivers of HIV/AIDS orphans. In addition, this research sought to inform structures that may be of support to the caregivers. Based on these goals the following sections look at the stressors that may impact caregivers of HIV/AIDS orphans and ways of coping that may be of assistance to these caregivers.

2.6. The concepts of stress and burnout in caregiving

According to the Joint United Nations program (UNAIDS 2008) the physical and psychosocial impacts of caregiving on women caregivers' wellbeing are rarely acknowledged as women often ignore their own health concerns. In addition, many caregivers are living with HIV themselves. As a result of the complex demands associated with caregiving in the HIV/AIDS field, the emotional stress on caregivers of all ages and gender can be significant.

2.6.1. Stress

The transactional model defines stress as the outcome of interaction between organism and the environment. Within this model an event in the environment is considered to be a stressor only if the organism's appraisals of the event, and of its own resources, suggest that it is threatening or disturbing (Singer & Davidson, 1986). Stressful experiences should therefore be viewed as person-environment transactions. These transactions are dependent on the impact of the external stressor. Stressors are demands made by the internal or external environment that upset the environmental balance, thus affecting physical and psychological well-being. Action is then required in order to restore the balance (Lazarus & Cohen, 1977).

According to the Aids Alliance (2007) caregivers caring for HIV/AIDS orphans may experience stress for a variety of reasons. These include concerns regarding adequate food and clothing, the high cost of medical fees, and inability to pay school fees for orphans (CHG, 2005). Cooper (1983) identified the following major work stressors in the health care environment:

1. Job specific stressors such as dangers, work satisfaction and workload.

2. The nature of the role played within the organisation and problems associated with this role, including role ambiguity, conflict, and territoriality.
3. Career structures and processes including prospects for promotion and job security.
4. Work-based relationships, including levels of emotional and social support from colleagues, bosses, and subordinates.
5. Organisational structures and flexibility, including real participation in decision- making.
6. Pressures on family life resulting from work.

Armstrong's (2000) research substantiated these findings and further showed that much of the stress experienced by caregivers in the field of HIV/AIDS is related to the nature of the work itself. HIV/AIDS caregivers are confronted with an incurable condition that kills largely young people, causes terrible suffering and is heavily stigmatized. However, stress may also be caused by organisational factors, which include the way a care programme is designed and managed. The most commonly reported causes of stress among caregivers working with AIDS programmes include:

financial hardship; oppressive workloads; over-involvement with people with HIV or AIDS and their families; personal identification with the suffering of people with AIDS; the unmet needs of children; lack of an effective voice in decisions that affect them and their work; inadequate support, supervision and recognition of their work; inadequate training, skills and preparation for the work; lack of clarity about what the caregiver is expected to do; lack of referral mechanisms; and lack of medication and health care materials (Cooper, 1983).

Locke and Taylor's (1990) research concerning stress and the work environment found that individuals seek to derive certain values from work such as a sense of purpose, enhancement

of self-concept, material values, achievement-related values, and social relationships. These authors therefore suggested that workers experience stress when the work environment conflicts with an individual's attainment of these values.

When an individual feels that stress is exceeding his or her resources and hence threatening to his or her well-being (McCausland & Pakenham, 2003) the stress starts to gradually build up. Burnout occurs once the stress has built up to such a level that the individual is no longer able to cope. As a result the person's physical and mental health, personal relationships and standards of care may all suffer (Aids alliance, 2007).

2.6.2. Burnout

Burnout was first described by Freudenberg (1974) as a state of fatigue and frustration arising from unrealistic and excessive demands on the personal resources of health and service workers. Freudenberg (1974) suggested that a person attempting to achieve unrealistic expectations imposed either socially or internally, may become physically or mentally exhausted. Bennett, Kelaher and Ross, (1994a) described burnout in the context of HIV/AIDS care as being more of a function of the situation, social context and nature of the job rather than a function of the nature of the person doing the job. Furthermore, Defilippi (2003) suggested that the difficulties experienced by orphans and other children made vulnerable by the epidemic further exacerbate the risk of burnout for AIDS caregivers in developing countries.

Maslach (2003) described burnout in the work environment as a prolonged response to

chronic emotional and interpersonal stressors in the workplace. Miller and Bor (1991) stated that, among a variety of other possible reasons, burnout can occur due to the discrepancy between the demands of a job and the ability of the worker to fulfill these demands. Maslach (2003) identified exhaustion, feelings of cynicism and detachment from the job, and a sense of inefficacy as the three key dimensions of the stress response. This interpersonal framework of burnout emerged from early research focusing on caregiving and service occupations in which the core of the work involved the relationship between provider and recipient. This multidimensional model focused on the individual's emotions and on the motives and values underlying his or her work with the recipients (Maslach, 2003).

The conceptual impact of the burnout model can be best observed in the cynicism dimension of burnout. Within this dimension the person's attempts to distance him/herself from aspects of their work can be viewed as an individual coping response to stress. However, when viewed from an interpersonal context the response can be seen as dysfunctional and has negative consequence for other people such as clients or colleagues (Maslach, 2003).

In order for the caregivers' to maintain sound physical, mental, and emotional well-being they need to find ways to cope with the stress that they experience on a daily basis in their field. The following section discusses the concept of coping and highlights coping strategies that are aimed at regulating stress in order to achieve positive outcomes.

2.7. Coping

According to Dorz et al. (2003) health caregivers dealing with people suffering from serious illness and caregivers exposed to multiple deaths are at risk of developing work-related

psychological disorders. Stress and burnout can be managed by developing personal coping mechanisms and organisational strategies (Aids Alliance, 2007).

The earliest concept of coping was based on the ego psychology school of thought, which defined coping as realistic and flexible thoughts and acts that solve problems and thereby reduce stress. In this model coping consists of cognitive and behavioural efforts aimed at managing external and/or internal demands that are experienced as exceeding the person's resources (Lazarus & Folkman, 1984). These cognitive and behavioural efforts are continuously changing as a result of continuous appraisals and reappraisals of the person-environment relationship, which is also continuously changing (Folkman & Lazarus, 1990).

Donal, Lazarus & Lolwana (1997) framed coping as a process of interaction between an individual and an environment, each with its own set of resources, vulnerabilities, potential and needs. The coping model proposed by Lazarus represents the most sustained, prolific, and systematic attempt to understand coping (Van Egeren, 2000). This coping model describes two forms of appraisals, primary and secondary appraisals.

Primary appraisals focus on the emotional aspect of coping with distress. For instance, if a person's self-esteem is threatened there is a potential for shame or anger as well as worry or fear. However, if a person's physical health is at stake worry and /or fear is likely to be dominant. In secondary appraisal the individual's concern is focused on what to do or how to cope in his/her environment. Appraisals of person-environment relationships are influenced by the person's characteristics such as pattern of motivation, beliefs about oneself and the

world, and recognition of personal resources for coping such as financial means, social and problem-solving skills, health and energy. Hence different individuals will perceive situations differently. A person's appraisal of a situation has a direct influence on the kinds of coping style adopted for survival (Folkman & Lazarus, 1990).

Folkman and Lazarus (1990) further classified coping processes that are directed at changing the situation that is causing the distress as problem-focused coping processes. In contrast, coping strategies that are aimed at regulating the distress are known as emotion-focused coping strategies. Both problem-focused and emotion-focused coping strategies are needed to manage the demands of stressful encounters.

According to Zeitlin and Williamson (1994) coping responses can be located on a continuum from consistently ineffective to consistently effective depending on the person and the situation. Bennett et al. (1993) studied the influence of coping styles on reported levels of burnout and found that coping style was a major determinant of burnout. The study found that the use of external rather than internal coping mechanisms was predictive of higher levels of burnout. In a separate study Martin (1990) found that coping styles involving cognitive and behavioural engagement were associated with higher burnout and greater intentions to discontinue working in the AIDS field. According to Bennett et al. (1993) the external coping strategies included fatalistic attitudes, and reliance on faith, prayers or miracles, whereas internal coping strategies ranged from expression of feelings and emotions, patience and time-out in working in the AIDS field.

Other researchers (Armstrong, 2000; Cohen & Syme, 1985; D’Cruz, 2002; UNAIDS 2008) have also investigated support as a coping mechanism for caregivers in the AIDS field. The following section focuses on available support structures and the support needed to help alleviate negative stress effects on caregivers in the field of HIV/AIDS including caregivers of AIDS orphans.

2.8. Support structures needed for caregivers of HIV/AIDS orphans

2.8.1. Social support

In the context of HIV/AIDS social support appears to be of significant importance for the cares of those affected and living with HIV/AIDS. Work by D’Cruz (2002), UNAIDS (2008), and Armstrong (2000) cited the importance of social support for caregivers in the AIDS field. This social support system usually consists of the extended family/relatives and friends (D’Cruz, 2002). According to Cohen and Syme (1985) positive social support is associated with better health outcomes, better coping, and less negative effects of stress.

2.8.2 Economic support

Accessing existing external financial support is a challenge for many caregivers. Due to the high rate of unemployment many South African households rely on pensions as their only source of income. Where social grants are available (e.g. foster care grants) access can be problematic as many guardians cannot trace their dependents’ remaining living parents (i.e. an absent mother or father) in order to obtain signatures on the required documents. In addition, many guardians do not have their own documentation in order and therefore cannot access grants.

Caregivers make use of various strategies to pay for medical interventions and other care costs, these strategies include taking on extra work, selling assets, taking children out of school to save on school fees, and borrowing money (UNAIDS 2008). Expanding economic support to caregivers by increasing their access to affordable basic shelter, land to grow crops, and other income-generating opportunities (UNAIDS, 2008) may help alleviate the burden of financial costs of caregiving as well as poverty in the wake of HIV/AIDS.

2.8.3 Psycho-social support

Caregivers of all ages and genders experience significant emotional stress in the context of HIV/AIDS. These caregivers need to be recognised and valued and their contribution to the public health sector and other organisation needs to be acknowledged (UNAIDS, 2008). In addition, the emotional impact of caregiving needs to be acknowledged and the overall health and specific psycho-social needs of caregivers, in particular older women and young girls, should be addressed through the provision of counselling (UNAIDS, 2006). Opportunities need to be created for the caregivers to participate in decision-making processes related to the work they do so that they can recommend their own solutions to ease their burdens (Armstrong, 2000; UNAIDS, 2000). Finally, Armstrong (2000) noted that involving and encouraging the families and communities to share the responsibility for the care of their loved ones helps alleviate the emotional burden of care on the caregivers.

2.8.4 External support

Caregivers need information on HIV prevention and care, access to basic supplies (blankets, aspirin, sleeping mats, etc.), training, and referrals for medical care. They also require social

assistance to support HIV/AIDS orphaned children (UNAIDS, 2006). Furthermore caregivers need a clear understanding of their duties and the limits of their responsibility for any client.

Caregivers also need to know who or where they can refer clients to when the client's condition calls for greater expertise or when they are unable to manage the situation alone. Good communication and referral mechanisms within AIDS care programmes are essential. Programmes should aim to strengthen their own foundations and create a supportive environment for caregivers at every level through networking and partnerships with other relevant organisations and individuals (Armstrong, 2000).

Organisations and individuals working with caregivers should ensure that the caregivers are involved in the design, implementation, and monitoring of HIV prevention, treatment, care, and support programmes at the national and community level (UNAIDS, 2006). Research suggests that caregivers who are not supported by programmes face many challenges including caring in a void of training, and lack of support from other programmes including material inputs like gloves and medication. Caregivers also need to have access to medical care and the health system for themselves and their dependents. These facilities should be easily accessible without barriers such as long waiting times, transportation difficulties, and inaccessible services (UNAIDS, 2008).

2.9. Conclusion

This chapter reviewed literature concerning the role of caregivers in the HIV/AIDS context. It examined the psychological impact of caring on the caregivers of HIV/AIDS orphans. A

general systems framework was adopted in order to explore the lived experiences of the caregivers.

Systems theory is considered general because it takes into account numerous systems that interact with other systems. General Systems Theory also seeks to gain a holistic view of a phenomenon (Covington, 1998) and explores people's relationships with their environments. The use of this theory allowed the researcher to understand the informal caregivers' experiences in relation to the broader systems/organisations that also influence their work and are part of their work and mental well-being.

The literature suggests that the majority of caregivers in the HIV/AIDS field are women. These women are grandparents; aunts, neighbours, community members, and young women and girls. Although it is less well documented males and young boys also occasionally adopt the caregiving role. A lesser but not insignificant number of men do provide care in the home and volunteer in home-based care programmes. However economic, social and cultural patterns place males in more favourable positions to cope with the impact of HIV/AIDS caregiving.

Research shows that the caregiving burden in the context of HIV/AIDS results in financial and psychological strain on the caregivers. Research further suggests that this stress is due to organizational factors and major work stressors (Armstrong, 2000; Cooper, 1983).

The most prominent model in stress evaluation and coping is based on the transactional stress coping model developed by Folkman and Lazarus (1990). In the transactional model stress is

defined as the outcome of interaction between the organism and the environment. An event in the environment is considered to be a stressor only if the organism's appraisals of it, and of its own resources, suggest that it is threatening or disturbing (Singer & Davidson, 1986). When an individual appraises a stressor as exceeding his or her resources and hence threatening to his or her well-being (McCausland & Pakenham, 2003) that individual's stress levels rise, eventually resulting in an inability to cope and burnout. The person's physical and mental health, personal relationships and standards of care are all likely to suffer as a result of burnout (Aids alliance, 2007).

Freudenberg (1974) characterized burnout as a state of fatigue and frustration arising from unrealistic and excessive demands on the personal resources of health and service workers. Freudenberg (1974) suggested that a person attempting to achieve unrealistic expectations, whether imposed socially or internally, may become physically or mentally exhausted. Bennett et al. (1994a) described burnout in the context of HIV/AIDS care as a function of the situation, social context and nature of the job rather than of the nature of the person doing the job. In addition, Defilippi (2003) suggested that the difficulties experienced by orphans and other children affected by the HIV/AIDS epidemic further exacerbates the risk of burnout for AIDS caregivers in developing countries.

The vast number of stressors experienced by caregivers in the HIV/AIDS field necessitates the development of specific ways to cope with the stress experienced. , Caregivers need to find ways to cope in order to maintain sound physical, mental, and emotional well-being. Donald et al., (1997) characterised coping as a process of interaction between an individual and an environment, each with its own set of resources, vulnerabilities, potential and needs. This coping model includes two forms of appraisals, namely primary and secondary

appraisals. Primary appraisals focus on the emotional aspect of coping with distress. In contrast, secondary appraisals focus on what to do or how to cope in a specific environment. This form of appraisal also includes an appraisal of the response to a specific action, which in turn influences the kind of coping style to be adopted for survival (Folkman & Lazarus, 1990).

Finally, social, psycho-social, financial, and external support for caregivers is important within the AIDS field. This support enables caregivers to play a physically and psychologically demanding and yet vitally important role in the fight against HIV/AIDS.

CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

3.1 Introduction

This chapter begins by stating the aims of the research and outlining the research questions. The methodology employed in the present study is then discussed. The chapter then discusses the research design and describes the participants and the sampling technique. A description of the data collection and data analysis follows. The chapter ends with a discussion of the ethical considerations relating to the conduct of this study.

3.2 The aims of the study

The primary aim of the study was:

- ◆ To investigate the psychological impact of providing care to children orphaned by HIV/AIDS.

The specific research questions addressed in this study were:

1. What are the experiences of the informal caregivers caring for HIV/AIDS orphans and other children made vulnerable due to HIV/AIDS?
2. What motivates the caregivers in their caregiving role?
3. How do caregivers deal with their daily experiences, and emotions, as well as manage any stressful situations inherent within their caregiving role?

4. What support structures are available for the caregivers?
5. Do these support structures help caregivers cope in their work environment?

3.3 Research approach

A qualitative research method was chosen for the study. Qualitative research seeks to gain an understanding of a given research problem or topic from the perspective of the local population (Mack & Woodson, 2005). Qualitative research designs are naturalistic, allowing the researcher to gain both depth and detailed information concerning the phenomenon of interest without manipulating the research setting (Strauss & Corbin, 1990).

Frankel and Devers (2000) characterised qualitative research as an inductive process that consists of describing people and groups' particular situations, meanings and experiences. According to Esterberg (2002) qualitative methods allow for the telling of detailed stories about a small number of cases. Qualitative research thus makes it possible to gain insight into the participants' lived experiences by understanding what they mean to the individuals, exploring how people interact with each other and looking at how they interpret and interact with the world around them.

Commonly used qualitative research methods include participant observation, in-depth interviews, and focus groups. Each method is particularly suited for obtaining a specific type of data (Qualitative research methods overview). The current study made use of a semi-structured method of data collection, where in-depth interviews were employed to explore the

phenomenon. In-depth interviews are used to collect data relating to individuals' personal histories, perspectives, and experiences, particularly when sensitive issues are being explored (Mack & Woodson, 2005).

Qualitative methods are typically more flexible than quantitative methods. Qualitative methods allow greater spontaneity and adaptation of the interaction between the researcher and the study participant. The method of data collection chosen for this study allowed for the use of open-ended (rather than close-ended) questions. With open-ended questions participants are free to respond in their own words and these responses tend to be more complex than simply agreeing or disagreeing with a researcher's statement.

In addition, the relationship between the researcher and the participant is often less formal in qualitative research than in quantitative research. In qualitative research participants have the opportunity to respond more elaborately and in greater detail. Qualitative researchers also have the opportunity to respond immediately to what participants say by tailoring subsequent questions to address information the participant has provided (Mack & Woodson, 2005).

3.4. Research design: A phenomenological study

A phenomenological research approach was chosen for this study. According to Van Manen (1990) phenomenology is an exploration of the essence of lived experience. Lester (1999) and Creswell (1999) further explained phenomenological approaches as based in a paradigm of personal knowledge and subjectivity, and emphasised the importance of personal perspective and interpretation.

In the human sphere phenomenological research normally translates into gathering 'deep' information and perceptions (Lester, 1999). Creswell (1999) characterised this form of research as gaining access to individuals' world experience through inductive, qualitative methods such as interviews, discussions and participant observation, and representing the information gained from the perspective of the research participant(s). Phenomenological and associated approaches are frequently applied to single cases or deliberately selected samples.

Another important principle of phenomenological research is phenomenological bracketing. Bracketing is a term that was derived from Edmund Husserl for the act of suspending judgement about the natural world. Husserl insists on an objective reality, however states that as subjective experiencing individuals, we bracket, limit and define that objective world (Moustakas, 1994). In phenomenological research the person's report of their life experiences is what makes it valid. However, as a researcher I am also framed by my own subjective views. These may stem from being a sister of orphaned children and by being a woman. Phenomenological bracketing becomes significant for the theoretical framework of the study the General systems theory. General systems theory is also of the notion that the subjective reality is shaped by each individual's reality of a phenomena.

3.5 Research participants

Qualitative research makes use of a small number of cases to study a phenomenon in-depth (Lester, 1999; Patton, 1997). A sample (subset) of a population is selected for inclusion in the study. This sample is selected in accordance with the research objectives and the characteristics of the study population (Mack & Woodson, 2005). The current study sought

to explore the psychological impact of caregiving by gaining an understanding of the participants' experiences of caregiving.

A total of eight informal caregivers participated in the study. The participants were chosen from the Khanyiselani Development Trust drop-in care-centre. The Khanyiselani organisation is structured around a walk-in centre within the community that coordinates home-based care services. The organisation is volunteer-run. The volunteers (including the caregivers) are compassionate community members who come from different backgrounds and their sole intention is to help and support those in need.

The responsibilities the caregivers have to fulfil include grooming, bathing, feeding, educating the family concerning caring for the clients, giving health education and social support to clients and family members, assisting families in receiving food parcels where necessary, and assisting with medication and accompanying patients to clinics or hospitals. In addition, the organisation provides morning and afternoon meals to school going and pre-school going orphans and other vulnerable children. These children are also assisted with their schoolwork and are involved in enrichment programmes. Volunteers monitor the children's home circumstances on a regular basis and refer cases to social welfare if necessary.

Seven of the participants were female and one of the participants was male. According to UNAIDS (2008) although the majority of caregivers are women, a significant number of men also provide care in the home and volunteer in home-based care programmes. Thus, the inclusion of a male participant in this study was important as it helped the researcher to access the underlying perceptions of both male and female caregivers in the context of caring

for HIV/AIDS orphans and other vulnerable children affected by HIV/AIDS.

The participants' ages ranged between 26 and 46 years old. The participants were all recruited from a volunteer-run non-profit organisation. All the participants function as caregivers to orphans of HIV/AIDS and children who are affected by HIV/AIDS. All of the children to whom the caregivers provide care are aged between 0 and 17 years old. The number of years the participants had been working as informal caregivers ranged from one to seven years.

The participants had all received some form of training in caregiving. The level of training ranged from a 4 to 10 day course, a one week course and a one month course. The amount of training received by the caregivers varied in relation to their level of experience and the availability of training resources. Some of the participants in this research study had only attended one training course, while others had attended five or even seven training courses.

3.6 Data collection

According to Strauss and Corbin (1990) the researcher is the primary information collection instrument in qualitative research. In this form of research valid understanding of experiences can be gained through accumulated knowledge acquired first hand by a single researcher (Winston, 2003). The most commonly used qualitative research methods include participant observation, in-depth interviews, and focus groups. Each method is particularly suited for obtaining a specific type of data (Mack & Woodsong, 2005).

This study made use of a semi-structured questionnaire as a method of data collection involving the use of in-depth interviews to explore the phenomenon under investigation. Interviewing is important data collection method as it allows the researcher access to the knowledge and life experiences of others (Weiss, 1994). Interviewing also enables interviewers to learn about setting that would otherwise be inaccessible. Qualitative research interviews are replete with open-ended questions. The answers to these questions should take the form of a narrative by the respondent about his/her experiences. This provides the researchers, and eventually the readers, a more complete picture of the perspective of the subjects of the study (Weiss, 1994).

In preparation for the qualitative interviews, a simple outline of the topics to be explored in the interview was used as a research guide. This guideline is useful if the respondent seems to be veering from the topic (Weiss, 1994). The interview process allows the interviewer and the respondent to form a relationship within the interview, and this can lead to the process having the feel of a conversation, which enables the respondent to be more at ease and therefore more likely to divulge valuable personal information (Weiss, 1994).

The interview instrument used in the current study consisted of a semi-structured questionnaire that aimed to obtain the following information about the research participants:

- Demographic information: date of birth; age; gender; marital status; ethnic group; highest level of education; home language; number of dependents in the household; work background; age of clients with whom the participant works; duration working as a caregiver; previous employment; and any training received in the field of HIV/AIDS.
- Caregiver experiences in the field of HIV/AIDS including: frequency of contact with

clients; HIV status of clients; stressors or difficulties experienced in the field of work; feelings of responsibility in relation to clients' suffering; emotions experienced; adequacy of training; and motivation for being a caregiver of HIV/AIDS orphans and children affected by HIV/AIDS.

- Support system available for caregivers. This involved an open question relating to the type of support available and the usefulness of that support.
- Coping as a caregiver. This section of the questionnaire looked at whether there was a balance in the time spent in the field of work and with their immediate families, their coping mechanisms in dealing with work challenges, symptoms of stress (emotional or physical), frequency of stress symptoms, anxieties related to working in the field of HIV and AIDS, and differences in levels of attachment towards clients.

3.7 Research Procedure

In order to conduct qualitative research the researcher works in close contact with the community leaders and gatekeepers (official and non-official authorities) in developing a plan to identify and recruit potential participants in the area for the study. Permission to access the participants at Khanyiselani community based care-centre was requested from the founder of the Khanyiselani development trust. Once permission was granted for the researcher the researcher was provided with contact information for the community caregivers' supervisor. Telephonic discussions were held with the supervisor and a preliminary meeting with the participants was scheduled with the assistance of the supervisor. During this first contact session with the potential participants the purpose of the study and the criteria for participation were explained. The voluntary nature of participation was emphasised. A suitable sample was then selected.

This study made use of purposive sampling. Purposive sampling is a commonly used sampling strategy that groups participants according to preselected criteria relevant to a particular research question. With this sampling method the sample size is not always fixed prior to data collection as it depends on the resources and time available as well as on the study's objectives (Mack & Woodsong, 2005).

The research interview process was conducted over three days. Six of the participants were interviewed on the first day while the remaining two participants were interviewed on the second day. These final two participants had been unavailable for interviews on the first day. On the third day a debriefing session with the participants was arranged. This debriefing session served to conclude the process and provide support for the participants as for some the interview experience was quiet emotional.

Prior to the interviews written consent was obtained from the participants. Permission was also granted to audiotape the interviews. The audiotapes of the interviews were used solely for the purpose of analysing the research. These recordings remain the property of the researcher. The informed consent was written in Xhosa in order to ensure that all the participants were able to understand the content.

3.8 Data analysis

All the interviews were audiotaped with the participants' permission. The data from the audio recordings was then transcribed from Xhosa to English before analysis. An independent person who was fluent in both languages (English and Xhosa) was asked to translate the transcripts from Xhosa to English. A second independent person was then asked to translate the transcripts back from English to Xhosa in order to ensure validity. The researcher, who

speaks Xhosa as a first language, also proofread the transcripts to ascertain validity of information in comparison to the original documents.

A thematic analysis approach was used to analyse the data. According to Terre Blanche and Kelly (1999) this form of analysis involves dividing the data and inferring themes as well as categorising data in the research material. The final account of the analysis is then conducted through developing the information through elaboration and interpretation of the data.

In addition to the above data analysis method a theoretical thematic analysis rather than inductive thematic analysis was used to give a more detailed analysis of aspects of the data. According to Braun and Clarke (2006) thematic analysis tends to be driven by the researcher's theoretical or analytic interest in the area, and the coding of data is therefore driven by a very specific research question.

Following the theoretical thematic analysis, a semantic approach was used to identify themes. In this data analysis approach the themes are identified within the explicit or surface meanings of the data and the analyst is not looking for anything beyond what has been written or spoken in the transcripts (Braun & Clarke, 2006). Ideally, the analytic process should involve a progression from description, where the data has simply been organised and summarised to show patterns in semantic content, to interpretation, where there is an attempt to theorise the significance of the patterns and their broader meanings and implications (Patton, 1990). This theory building often takes place in relation to previous literature.

3.9. Ethical considerations

Research ethics deals primarily with the interactions between researchers and the people they study. Research ethics help ensure that researchers consider the needs and concerns of the people involved in the study, that appropriate conduct of research takes place, and that a basis for trust is established between researchers and study participants. Some of these ethical considerations are discussed below (Mack & Woodsong, 2005).

- Respect for persons requires a commitment to ensuring the autonomy of research participants. Where autonomy may be diminished the researcher is ethically obliged to protect people from exploitation of their vulnerability. Informed consent is a mechanism for ensuring that people understand what it means to participate in a particular research study so that they can decide in a conscious, deliberate way whether they want to participate. Informed consent is one of the most important tools for ensuring respect for persons during research.
- Beneficence requires a commitment to minimizing the risks associated with research, including psychological and social risks. Beneficence also requires maximizing the benefits that accrue to research participants.
- Justice requires a commitment to ensuring a fair distribution of the risks and benefits resulting from research. The individuals who take on the burdens of research participation should share in the benefits of the knowledge gained.

For the purposes of this study permission to conduct the study was obtained from the participants and from the founder of the Khanyiselani Development Trust. Written consent was obtained from all the participants. This written consent related to the purpose of the

research, the expectations of the participant, the voluntary nature of participation and the right to withdraw from the research and the maintenance of confidentiality. The participants were also provided with the contact details of the researcher, and encouraged to contact the researcher if any questions or problems arose.

3.10. Summary

This chapter focused on the aims of the research as well as the specific research questions addressed by this research study. A phenomenological approach was adopted as the study involved an exploration of the lived experiences of informal caregivers. This study made use of a qualitative research methodology and the reasons for this methodological choice were discussed in this chapter.

The chapter then discussed the participants of the study and the data collection methods used in the study. The procedure for recruiting the participants and conducting the interviews was also described. Finally, the chapter concluded by discussing the data analysis procedure used and the ethical considerations of the study.

CHAPTER FOUR

RESEARCH FINDINGS

4.1 Introduction

This chapter discusses the findings of the research. These results are based on the thematic content analysis of the verbatim transcripts of the participants' interviews. The main themes that emerged from the findings related to the psychological impact of caregiving on the caregivers of HIV/AIDS orphans. Several eminent recurring sub-themes were also noted and these are discussed in this chapter.

4.2 Demographic information of the participants

Eight participants were interviewed in the study. Seven of the participants were female and one of the participants was male. The majority (four) of the participants were aged 36-39 years old, three were aged 40-46 years old, and one participant was aged 26 years old. Two of the participants were married, while the rest were unmarried. In terms of education two participants had senior certificates, four had Grade 11 education, one had Grade 10 education and one had a Grade 8 education.

Prior to assuming their caregiving roles, one participant worked at a construction company as an electrician for a year. One of the other participants had worked as a diesel attendant for three years. One of the participants had worked as a cashier for two years and had also worked as a security guard. One of the participants worked as an assistant for two years. Two of the participants had worked as general workers, one for seven years and one for a year and

a half. Two of the participants had no work experience. All the participants are currently not employed outside of their volunteer work at the centre.

Four of the caregivers had dual roles as caregivers of HIV/AIDS orphans and other vulnerable children due to HIV/AIDS (aged 0-17 years old) and as caregivers of adults infected with HIV/AIDS. The remaining four caregivers work exclusively with children. However it is important to note that in their caregiving roles all the caregivers interact with surviving family members and also offer support to these adults where necessary.

All of the caregiver participants have children of their own. One participant has four children, one participant has three children, three participants have two children, and three participants have one child. Two of the participants live with their husbands, one lives with her children and grandchildren, one lives without family or any dependants, one resides with her children and a family member, and the remaining three reside with their children. Three of the caregivers also volunteered the information that they are HIV positive.

4.3 Identification of themes

The themes were derived through an extensive reading through of the individual transcripts. Similar and contrasting patterns of expressions of emotions and notions of the experiences of the caregivers in the data were used to formulate the main themes of the study. The main themes identified in the interview transcripts were:

1. Poverty as a cause of psychological distress;

2. Overwhelming nature of the work;
3. The need of support structures to caregivers; and
4. Coping and the psychological well-being of caregiver

These four main themes were identified based on questions asked in relation to the overall research question that focused on caregiver experiences, their available support system; and the coping mechanisms used.

During the interviews the caregivers referred to the HIV/AIDS orphans and other children affected by HIV/AIDS as clients. This term was used as the caregivers provided care not only to the children but also to their sick parents and other family members.

4.3.1 Theme 1: Poverty as a cause of psychological distress

All the caregivers highlighted poverty as the major cause of distress impacting both them and their clients. The caregivers explicitly mentioned that they come from poverty stricken homes and that they find it very challenging to work in the HIV/AIDS field as a result of poverty. All of the caregiver participants had no employment other than being volunteer caregivers. Most of the caregivers are breadwinners in their households in that they support their own families with whatsoever incentive they may be rewarded with for their duty at a given time and the burden of being financially destitute impacts on their relationships with significant others.

Participant A: “The problems we normally face a lot in the community is poverty, maybe to make an example, when we arrive in a home and we find people are hungry there being no food. Because we see children very hungry we also cannot tolerate the pain”.

Participant B: “The most difficulty we facing is poverty. In other homes no one is working. People are sick due to this current disease. Now that there is no work food is scarce”.

Participant C: “The most devastating problem is poverty. One finds that the children at home have no basic food to sustain them and make them healthy. This makes the recovery process of the client to be slow as they resist taking treatment”.

Participant D: “It hurts me to see what this illness is doing to the children. Especially when you see the poverty in their homes and children having to go to bed without eating whilst I cannot help them ... it causes me heartache”.

Participant E: “There is a lot of poverty in our community and a lot of suffering. I, also as a caregiver am a person who is poor who does not have much. Thus there is always frustration when I cannot do much for my clients. Before I became a caregiver I had the support of my family as I also could support them financially. Now that I am a caregiver my family is distant because I cannot give them any financial support as I did before”.

Participant F: “Poverty in our area is really a cause of much heartache on top of pain caused by this disease”.

Participant G: “I am able to identify the children in need by seeing that they are not wearing any shoes or any jersey in extremely cold weather”.

Participant H: “Poverty is a problem as a result of lack of money or elders not working. This is a huge burden because it takes a long time to get their grant money approved; and when

the money is available it used for the whole household and not the child and hence does not become enough to support all of them”.

The majority of caregivers reported experiencing distress and despair as a result of being unable to provide for clients basic needs, witnessing their suffering as a result of poverty and even witnessing clients dying as a direct result of poverty. Some of the specific circumstances the caregivers highlighted included clients defaulting on treatment due to hunger, clients missing their hospital appointments due to unavailability of transport fare, children becoming street children in attempt to find a more nurturing environment, children not receiving education due to missing school, and the lack of basic necessities such as clothing. The caregivers stated that all of these circumstances were the direct result of insufficient access to economic resources.

Participant A: “If they do not have food then they do not take treatment. Others do default so we guard them in that way. We check because you find that others hide their pills underneath their pillows or underneath their bed when they do not want to take their pill”.

Participant B: “The child then goes to the streets in seeing that there is food there than at home”.

Participant C: “Then there is an issue of not being able to take our clients to hospital for help in time due to ambulances that will arrive very late after being called, or which do not come at all. Some clients even die because of the lack of involvement from the ambulance people”.

Participant D: “There are times where the clients have to be taken to learn about the medication they take but because there is no money and we have no money and there is no transportation, a person gets left behind in the learning about the medication that would otherwise help them”.

Participant E: “At times when I see the suffering of these people I think of using my own money to help them. It is devastating then when I also have nothing to offer”.

Participant F: “Many times I feel like I need to do more but I also do not have much to offer when it comes to alleviating poverty and the suffering thereof”.

Participant H: “Another child asked me for shoes to wear and I had none for her at the time and I had no resource to get them. It hurt me deeply because it was as if I had let down the child”.

Some of the caregivers attempt to deal with the results of poverty by being more proactive. All of the caregivers indicated (either implicitly or explicitly) that they take actions to alleviate the distress and expend considerable amounts of effort in attempting to make the daily lives of their clients’ better.

Participant A: “On other occasions when we see that the situation is too bad we would go to our own homes and take food so that the person can have something to eat; so that the person can drink his pills. Then you find that you need to take your own child’s uniform if you have a child, shirts, socks, shoes etc. and give it to the orphan child so he wears something and goes to school”.

Participant B: “We also try of other means that a person who has been not getting a grant because they had been cancelled to be reinstated by asking the doctor for assistance. Even if it’s for three months so that the person can feed the children”.

Participant C: “When I have mealie-meal or vegetables at home, I’d take some to the homes where they are much needed; but I also cannot do this all the time as I may not always have much at home”.

Participant E: “At times when I see the suffering of these people I think of using my own money to help them”.

Participant F: “At times I can sacrifice all that is mine just for the other person ... it is difficult to separate myself from the other persons suffering”.

Many of the caregivers described feelings of hopelessness and disappointment as a result of not being able to contribute to their clients’ lives by alleviating poverty. Some caregivers mentioned feeling as though they were responsible for their clients’ stressful situations and felt that not being able to help their clients was the same as not being able to help themselves.

Participant C: “I feel terribly bad inside as if I am failing my clients. As a result I find it difficult to sleep at night because of this. I do not know how to handle the frustration rather than talking to someone or asking for assistance or ideas from a colleague”.

Participant D: “I wish I could do more for them but it does not happen that way. I suffer deeply when this happens”.

Participant E: “people get registered here at work so that we give them food parcels. When we have registered them, we are then not able to give them food parcels, food does not arrive and it is as if we are playing around with people. Now I even become afraid of looking at the people in the eyes because I had promised to help them and these children and parents have no grant money, no one works for them, nothing. At times when I see the suffering of these people I think of using my own money to help them. It is devastating then when I also have nothing to offer”.

Participant F: “there are children whom I tell myself that I cannot let the day pass without going to check on them and to make sure they are going to go to bed having eaten”.

In contrast to the extracts above, some of the caregivers detach themselves from their clients' suffering. They are able to do this because they believe that their work efforts are sufficient in ensuring that the children's suffering is alleviated.

Participant A: “There are ups and downs like in any other place. But the thing that makes me happy is when clients see the need of taking treatment and showing interest in their wellbeing”.

Participant G: “I work as hard as I can to make sure that the children are well cared for. I only get angry when the families do not seem to be on the same page with us in wanting a better life for the children and misusing their grant funds”.

Participant H: “I also do not think the children blame me for what is happening to them. I sit and talk to the child and give them support. I become very glad when the child is satisfied by my help even if it is just to talk with them”.

One of the caregivers reported feeling liable for the clients' suffering. However, this caregiver felt that the clients' suffering was not just her responsibility but was also the result of the failure of availability of other supportive structures that should play a significant role in assisting with the clients' well-being.

Participant B: "At times ... especially when I felt as though I should be able to help them and I could not. Like having food available for them, or when they do not get grants, and when I see the pain caused by poverty in their daily living and I cannot do anything to change that. Another thing is that a lot of clients die. It is because you find the person unable to even get up and the ambulances take forever when called. At other times you even find yourself being resentful to the ambulance people because of the pain you are feeling from the loss of your clients".

The caregivers described their experiences of working in a poverty stricken community as a never ending battle, and found the work to be overwhelming. The caregivers are placed in a vulnerable position as they find themselves going to great lengths to try to assure their clients' well-being.

4.3.2 Theme 2: Overwhelming nature of work

This theme is based on the caregivers' expressions of the impact of their work on their emotional and physical functioning. The caregivers reported recurring patterns of having to

take on many responsibilities for each client and many different clients a day. The client load is dependent on the amount of work that needs to be performed and the number of clients that need to be assisted.

The caregivers' duties included bathing clients, cooking for, feeding and grooming their clients. In addition, the caregivers assume responsibility for making sure that their clients receive their medication and use it appropriately. Caregivers also have to make trips to hospital for their ill clients, take them to hospital when they are very sick, and accompany their clients to the clinics to learn about treatments and living a healthy lifestyle. Caregivers also liaise with organisations such as the Department of Home Affairs and Social Welfare in order to ensure that their clients have birth certificates and proper identification so that they are able to receive grants.

Many of the caregivers reported that the magnitude of their workload impacted on their time with their significant others. However, some of the caregivers were able to balance the two domains of their lives in their daily living.

Participant A: "The clients are a lot and one cannot see them all in one go. Also the work is a lot too and the problems are different. For instance you may go see a client at home and then find you have to take the client to hospital and stay the whole day for that client in hospital. You may find that this child lives with a very sick parent or he or she lives with the granny. The granny does not know a lot in caring for the child, she is staying with the child and not

taking him or her for treatment. We then take the child to hospital and he is started on treatment”.

Participant B: “It is difficult to work with orphans because you find that besides the illness they have many problems. You find that a person has his or her personal problems that he or she cannot talk about to others. You discover that a child becomes a street kid because of the difficulties he encounters”.

Participant C: “As a caregiver I have found that I have to take on many duties at once and also that each day and each person has different needs. I have less time for my children and grandchildren. When I get home I am exhausted emotionally and physically and thus I cannot devote as much time I want for my family”.

Participant D: “My work involves assisting people and children who are sick in the community. I assist the whole family with their difficulties. I stay and cook for the sick, bath them and clothed them. I visit my clients daily. There isn’t enough time for my family. Because of the need of work and because we depend on the money, it is important that I work for my children and family. My children also get left alone when I am at work”.

Participant E: “I work with children who have no parents, or whose parents are sick, and school - going children. It is hard work and stressing and tiring most of the times because the processes can take a long time and the children are in need as in urgently. It is even difficult for me as I am doing this work to try and improve the burden on them of having nothing so that they too can be like other children out there who have something...so that they can have a purpose to live in life, eh, yes”.

Participant F: “There those clients I even see on daily basis more than others. Especially if I have just met them, or those who are still very sick so they need to get treatment constantly”.

“Time with my family is not enough, it is much needed. Time for me and my child is not enough as I am tired when I get home to be with him”.

Participant G: “As a caregiver I have to make certain that the children are well cared for. That they are registered and are attending school; that they have grant money that they can use to get food at home, have clothes, and are able to go to hospital to get treatment. I have to visit my client’s homes constantly in order to make sure that there are still cared for and well. . When I see the hardships the clients face, I get headaches and feel the burden heavily inside me. It becomes worse when I had tried that the child’s life becomes better but they still suffering. It is disturbing and overwhelming when things are like this”.

Participant H: “Problem one meets is that some of these children live with their grandmothers. In this case one has to teach the grandmother on how to care for the child, and when to give them medication and how. As a result of this one cannot just go by once at this home. I have to do constant visits to check if the grandmother still remembers how to treat the child”.

The large volume of work results in caregivers experiencing both emotional and physical fatigue. Some of the caregivers expressed the need to share the responsibilities of caring for the clients. The caregivers felt that being assisted by the family members and the families showing some affection and nurturing towards the clients was very important. Lack of support from the families resulted in serious frustration for some of the caregivers.

Participant A: “we teach others at home ways of treating and supporting the child as well as giving them their pills. It can be frustrating then if people do not work with you and do as told because it is of benefit to the life and health of the person”.

Participant C: “It is also painful to see our client’s not being cared for and supported by their families when we are not there. It would be helpful to us if families could assist us as this could lessen the heavy load for us. Being a caregiver entails much work to be done and needs too much effort to be put in”.

Participant E: “One also realizes that the child is not in school and that one has to ask the parent to apply for a grant than the child to work so he can go to school. Parents find it difficult to agree to this as this is their daily bread. Some parents end up being angry with me, but what can one do except that I have to keep on begging them and making them see the importance of them getting a grant than for the child not to be at school as a result of working”.

Participant F: “what hurts is that even if we try hard to get grant money for the children the money ends up being misused by the guardians of the children. The children then suffer unnecessarily. This is very stressful I tell you. It makes me angry at times and even when I try to talk to the elders caring for the child at times it’s in vain and they never listen to what we say, that children’s health and life should be put first”.

Participant G: “The difficult and stressing thing is when it feels like the load is all on top of my shoulders. It gets stressing when I have asked family members’ to feed, bath, and give client’s medication but then they do not. It angers me to the core; the whole thing is just a headache now I have to start everything from the beginning. This tires me emotionally and physically”.

Although the caregivers indicated that it is important for the families of the clients to assist in the caregiving role, they also indicated that they rely on social and health departmental structures to share the responsibility for caring for their clients. For the caregivers it was apparent that it was important to have good working relationships with the different structures for the benefit and larger goal of making their clients' survival and lives better.

Participant B: "we even have a plea to the social workers that they ensure that this parents grant money does not get terminated as this prolongs death".

Participant D: "There are organisations, actually one from which I normally would ask for transport to take us to the clinic".

In addition to experiencing frustration many of the caregivers reported that they also experienced other negative consequences as a result of the overwhelming nature of their work. A significant number of the caregivers reported that the distress takes a toll on both their physical and emotional well-being. Symptoms reported by the caregivers include a lack of motivation, sleepless nights, poor appetite, and headaches.

Participant B: "It happens that one feels tired. When there had been something that affected me negatively I sometimes feel as though I am fed-up as though I could stop working. At times when I am very disturbed at work I would go to sleep without eating and I would just drink coffee".

Participant C: “Things we encounter do not make me cry as much as I used to. I do get headaches and sleepless nights. I feel that I have to help them and make them happy as much as I can. That is why at times I cannot even sleep as I try to make my clients lives better”.

Participant E: “Tiredness, sleepless nights, headaches are there. I would take the pain of my clients and make it my own”. I also do cry although not in front of my clients because of the suffering we see out there”.

Participant F: “I think the problem I have is that I would cry but not in front of my client’s. Also this is not a daily thing but I think I just get too affected by what I see out there. Another thing is headache, but it happens when maybe I got very frustrated at work due to some conditions I encounter”.

Participant G: “When I come back from work I feel exhausted even though I had not worked that much. I get brain tired and my body physically weak. Some days I cannot even sleep. At times I cannot even eat because of the situation I had to deal with before in the day, especially if I had seen a very ill client. Even while resting in bed it becomes difficult to fall asleep due to different thoughts raging in my head”.

However, some of the participants indicated that they were enduring and had adapted to their work conditions.

Participant A: “I think I have adapted well in my work after all these years that I do not go through a lot of that stuff”.

Participant D: “Apart from having headaches I have not experienced a lot of symptomatic problems. It is not something that happens often, it depends on how much I have used my mind, thinking hard and timeously”.

Participant H: “Work is hard and saddening but I haven’t experienced any conditions that actually hinder my performance at work”.

The overwhelming nature of the caregivers extended beyond just having to render physical duty. Through their interactions with their clients a significant number of caregivers expressed being emotionally involved with their clients.

4.3.2.1 Emotional involvement

Half of the total number of the caregivers spoke about being emotionally attached to their clients. Some of caregivers indicated that they even find themselves internalising their clients’ suffering and difficulties. The caregivers described experienced feelings of helplessness and distress related to their inability to help their clients.

Participant B: “I care for all my clients equally. Maybe that is why it becomes too much to see them in pain. The frustration overwhelms me, it is as if what happens to my clients happens to me and I cannot help myself”.

Participant D: “I see myself very close to the children because I think they are in need of love. Hence I constantly would check if the needs of the children are met. There are those

who are always in my mind and heart all the time. It is this reason why it becomes so difficult for me to see my clients living a difficult and painful life”.

Participant E: “I usually take in the pain of my clients and then it seems as if it is my own. Also these clients stick in my mind and heart and when things do not go well for them I feel I worry more and stress more about them”.

Participant F: “I get very affected by the pain I see in my clients but I do not allow them to see how affected I am. It is when I am on my own that I would cry in an attempt to rid myself of the emotions.”

However, some of the caregivers indicated that they are able to detach themselves to some extent from their clients’ suffering. This enables them to feel less responsible for their clients’ sorrow.

Participant C: “I devote my work as much as I can to all of them. I love them all in the same way”.

Participant G: “I feel I grow to care for my clients as equally as I can. I give my all for every child I get to meet. I do not want to love a certain child or care for them more than the other. I feel they all deserve equal care and love”.

Participant H: “I love all the children equally and I would like to think that I give each and every one of them all the necessary time they need for me to care for them. I want to give them equal treatment as I do not want other children to feel less important than others”.

One caregiver indicated that her years of experience enabled her to remain objectively firm and not emotionally coiled with her clients. Instead she uses her involvement with her clients to inspire them to live a better and positive life.

Participant A: "I am also HIV positive so I just loved working with people who are also affected by this disease and I feel connected to them. I can give people advice based on my experience".

4.3.3 Theme 3: The need of support structures to the caregivers

The caregivers all reported experiencing psychological distress as a result of their caregiving role. Although each caregiver reported unique experiences in relation to difficulties, all the caregivers reported that the difficulties they encounter impacted on their emotional, mental and physical well-being. Through the content discussions with the caregivers the caregivers all spoke about the importance of support when working in the HIV/AIDS field. The caregivers indicated that they require emotional, economic, external, and psycho-social support.

4.3.3.1 Emotional support

All the caregivers mentioned the need to be supported openly and keenly by their significant others, including their spouses, partners, parents, siblings, and children. The caregivers spoke of the importance of having someone with whom they can cry, who will understand their difficulties and be of solace in times of despair.

Those caregivers who indicated that they receive emotional support from their significant others stated that this strengthened and motivated them as caregivers. They were able to move forward despite the adversities in their working situation.

Participant A: “love is what is important; I mean that the father of my child told me he would not abandon me and would be supportive of my work”.

Participant B: “When I talk to my mother and tell her how difficult it is to work in this field, she tells me to hang on and that this is God’s gift to me after a long-time of not working, and now I have work which comes with dealing with people’s pain. My mother makes me stronger when she says ‘with perseverance there’s something to gain”.

Participant C: “I receive support from my sisters and children. They encourage me on daily basis”.

Participant G: “At home my younger sister came to stay with me and is very helpful in taking care of my children when I am not at home. It also helps to come back home and just have a distant person from everything to talk to even if there isn’t much she can do. However her listening and consoling helps me cope”.

Participant H: “I am also very lucky because at home my family supports and encourages me a lot. My husband and my children’s support strengthen me”.

Those caregivers who did not receive support at home stated that they feel deserted, and less grounded at times. They also frequently experience distress.

Participant D: "There is nowhere that I receive support. My family is distant and even in my marital home I do not receive as much support. I find myself very lonely. The father of my child is also distant from me that is why I feel alone".

Participant E: "There is no person whom I can say supports me or I speak to about the difficulties of my work. I live alone here my family is in the Eastern Cape. I have no one that I can talk to about the sorrow I see out there. It is all so difficult for me and with all the responsibilities I have".

Participant F: "I have noticed that I have more support from other caregivers than at home. My husband does not offer me much emotional support as I need. It is not nice situation for me but what can I do".

4.3.3.2 Economic support

The caregivers all emphasised the importance of economic stability. This was linked to their need for their subsistence. Some of the caregivers openly stated that they require the financial security as a result of health difficulties. Economic support was also important in order for the caregivers to sustain their human basic needs and the needs of those dependent on them. The caregivers also viewed economic support as being indicative of a sense of appreciation for their duty and acknowledgement of their role.

Participant A: "the money is not enough. It would be better if we could be paid more money"

Participant B: "At times we do get some incentive as a form of reward for our hard work which becomes very helpful as a source of living".

Participant C: “We occasionally get an incentive here at work. I would not lie it is not enough to sustain me or my dependents. It is also not satisfying that at times we go through months without anything, I mean how are we to maintain our lives, health and selves?”

Participant D: “At work, I can say the only support I get is when I get some incentive and I am able to cater for my family”.

Participant E: “Now that I am a caregiver and not earn as much as I did, I cannot send money back home. My family does not understand, they are distant from me, they do not support me. My need is to be financially secure so that I can also take care of myself and my health”.

Participant F: “For me it is to have financial stability. We go months without being paid here at work. Also, even when we do get paid at times it is very little. It makes it hard then to support myself and my families and to cater for our needs”.

Participant G: “For us caregivers to have a decent income so that we too can take of our health, our families, and other needs we may have”.

Availability of economic support would also result in a better life for the clients and possibly less bereavement and less grief. Most of the caregivers believed that the provision of economic support would result in food being made available to their hungry clients, access to hospitals, clinics and treatment for their clients, and education for the children so that they can live out their dreams and potential. The caregivers thus see economic support as providing contentment.

4.3.3.3 Psycho-social support

Dealing with the effects of HIV/AIDS is strenuous to those living with and affected by the disease. The effects are also devastating for those individuals who support HIV/AIDS sufferers. During the interviews with the caregivers it became clear that caring for HIV/AIDS orphans and vulnerable children has a large impact on the caregivers. The caregivers all emphasised the importance of personal support for their own healing and containment. The caregivers stated that although a supportive space is made available for them this space is not adequate as it does not allow all the caregivers to share their grievances and be heard. Many of the caregivers openly requested that therapeutic support be provided.

Participant B: “We were once taken for Eco-therapy. It healed us deeply and we forgot about the problems we usually are faced with to an extent that when we returned we hoped we would have someone available for us whom we could talk to when we come back from our work carrying burdens of our clients”.

Participant D: “I need support myself, in that I also have my own personal problems with regards to work and need someone who can give me advice and alleviate my stress”.

Participant E: “It is a wish to have our own counselling and a person to whom we could openly share all our burdens with”.

Participant H: “The most important for me is that we get someone to speak to about our hardships like a counsellor, as a way of alleviating the stresses we encounter”.

Some of the caregivers also mentioned the importance of receiving support from their supervisors and clients.

4.3.3.3.1 Management support

The caregivers stated that their emotional well-being is not solely dependent on therapeutic practices. Management practices and behaviour towards the caregivers was also seen as an important aspect of their work environment. The caregivers stated that they felt that management failed to acknowledge their roles or provide encouragement and gratitude. Most of the caregivers stated that insufficient support from the management adversely impacts their self-worth and that this negatively impacts their personal development as caregivers. These caregivers also reported that lack of support from management sometimes results in feelings of anger, lack of motivation, and a desire to give up on their work. However, the caregivers are able to use their hope for a better future and their own motivation to enable them to persevere in their work.

Participant A: “Here at home (the centre) the problem is not being appreciated. Even when you have used your own resources you do not get any acknowledgment. However if there is anything that is not done right it is easy to get harsh comments and be criticised. This makes me feel like giving up because the work is very difficult and with the lack of support needed, it really brings a person down”.

Participant B: “I would appreciate support from our management. Support for me is lacking in this area in the sense that I rely on one colleague for moral support at times or try as hard as I can to deal with the challenges I face on my own. If only we could be supported, be

shown gratitude for our work, we to can see ourselves as important people and be sincerely happy here at work.

Participant C: “I just need a thank you for my hard work at times. It pains me when it seems as though what I do is unseen and I am made to feel as though I am useless at times when I do not know how to handle some situations we meet out there”.

Participant E: “We work as hard as we can and see to many demanding issues; I work as hard as I can in trying to change people’s lives but then get no gratitude. It is as if more focus is on the mistakes one does than the good so you can be criticised”.

Participant F: “A ‘thank you’ for the hard work is very important. This makes you feel important, as an achiever and acknowledged especially by the superiors. Without this I feel unhappy at work and this adds unto the distress I already encounter in the field”.

Participant H: “I wish there could be open communication with our employers so that we are able to discuss matters affecting us at work; for our employers to come back to us with solutions that will make our work a bit easier for us”.

4.3.3.3.2 Recognition from the clients

The caregivers reported that they experience feelings of self-worth, personal accomplishment, and valuable validation of their being and work as a result of the gratitude they receive from their clients and their families. Some caregivers mentioned feeling ecstatic as a result of the appreciation shown by their clients for their recoveries and well-being. Some of the caregivers reported experiencing a sense of reward and recognition for their efforts. These experiences help the caregivers feel that they have a purpose in life.

Participant A: "The work is admired by people a lot and it makes me happy to hear people appreciating the work done. Even to hear people talk highly of me or wanting my assistance a lot makes me feel worthy and important".

Participant D: "I get my support from my clients. Apart from them I can say there is nowhere else I get encouragement from".

Participant E: "I am very pleased when I hear good news from my clients. It makes me feel adequate at work. I feel as if I had achieved something quite important in life."

Some of the caregivers stated that they receive solace and moral support from the other caregivers.

Participant B: "It so happens that at times I go to someone's home on my own and I am faced with the client's grief on my own. I would call my colleague so that we could talk. We talk and she tries to advise me".

Participant E: "I usually would ask from one of my colleagues to assist me and give me direction with problems I encounter in the field. This helps me because we work as a team in trying to find ways of solving the problem and so at least I do not feel as though I am alone in dealing with the clients' suffering and it certainly helps lessen the burden".

Participant F: "I have noticed that I have more support from other caregivers than at home. Speaking to other caregivers is very helpful though. They understand what I am going

through as they know and experience these things. They are able to give me ideas into how I can cope with a difficult situation. Most of the time I always bring my burdens to them”.

Participant G: “I like to speak with my colleagues when in need of support. It so happens that it becomes unbearable when I’m being criticised for the things I do in trying to help my clients. When this happens I turn to my colleagues for moral support”.

Participant H: “I get support from my colleagues. It helps a lot to have someone to talk to. This helps in that one is able to get different views on how to handle the difficulties that the children bring up; or if a situation needs to be acted upon, it becomes easier for it to be done immediately”.

4.3.3.4 External support

Seven of the eight caregivers interviewed felt that they needed further training in the field of caregiving. They stated that this training should take the form of workshops and skills training in order to allow for optimum caregiving. The caregivers also stated that the training would help them feel empowered to support and assist their clients. The training would also contribute to personal growth and help them to develop a sense of trust in themselves and in their duties.

Participant B: “It could help if there could be financial assistance for us to attend counselling skills workshops before we go to our clients”.

Participant C: “learning more about HIV/AIDS; being educated on how to talk well with children and be able to counsel them is my main need in order to feel effective in my job. At

times when things are hard and I do not know what to do I lack trust in myself of being adequate enough”.

Participant D: “I do have some courses on workshops done but when you out in the field it feels as though I could have learned more. More skills training and counselling is needed, as well as further knowledge about HIV/AIDS”.

Participant E: “I also need training on having skills on how to deal with children’s emotions, and also more education on being a caregiver in the field of HIV/AIDS”.

Participant F: “I am still new in this field and further training and knowledge will help me cope better with my job”.

Participant G: “I feel that I need to attend more workshops and training especially about HIV/AIDS care and more knowledge on children’s welfare”.

Participant H: “I need more advanced knowledge into counselling children and taking care of their well-being. I still need more training and gain more knowledge that is going to make my work even much easier than now”.

One caregiver stated that as a result of her years of experience she felt adequately equipped to function as a caregiver of HIV/AIDS orphans and other vulnerable children.

Participant A: “I have been doing this kind of work for a long time. It is hard at times but I manage well and try to do my best”.

The importance of having extensive and enriching knowledge about working in the field of HIV/AIDS was clearly demonstrated by the fact that most of the caregivers reported experiencing no anxieties regarding being infected while working with their clients. This allowed them to experience less stress while caring for their clients.

Participant A: "When I work with my client I do not get scared about that because we were told how to protect ourselves".

Participant B: "I tell myself that it is not possible as we wear gloves. The educational programmes we have help us understand".

Participant F: "No not at all. I am not even affected by what some people may say about working with HIV/AIDS orphans and vulnerable children. I know how to take care of myself and what I need to do to be safe, so no I am not scared at all".

Participant G: "I know what precautions to take to protect myself and it is knowledge out there that it is not that simple to infect yourself while working with sick clients".

Participant H: "I have no fears. I wear gloves when I have to take care of a person, maybe washing them, apart from that I cannot get infected by being with and talking to the children".

Two of the caregivers reported that they are anxious while working with their clients. However, this anxiety was related to a lack of resource material (which prevented the caregivers from taking the necessary precautions) rather than to a lack of education or training.

Participant B: “When you have to take hold of someone I first check if there isn’t any open scar in me. It is because it was said that it does happen that they may be blood mixing so I get afraid. I’d take a plastic and wrap my hands with so that I do not touch with bare hands”.

Participant C: “I do get scared at times when there are no gloves to work with and I would have to use anything to wrap myself, and I could do this if it is far to go back to Khanyiselani for gloves as a client may need immediate assistance. The worry is less when I use gloves”.

4.3.4 Theme 4: Coping and the impact on psychological well-being of caregivers

The manner in which the caregivers cope with the daily impact of their job influences their mental and emotional states. The caregivers described different ways of coping. These different ways of coping have varying psychological consequences for the caregivers.

One of the caregivers appeared to be confused about the coping style she used to adjust to the caregiving role. However, the other caregivers indicated that they employ personal strategies such as having optimistic and positive attitudes, and being determined to achieve positive outcomes. The caregivers reported low levels of de-motivation and health and emotional issues.

Participant A: “through my devotion for the work and my love and passion for helping people in need”.

Participant B: “I tell myself that I can do the work put before me”.

Participant D: “I just have to be strong, be determined and persevere. I normally try to help the families by making vegetable gardens with them so that they can have something for themselves”.

Participant G: “By going to as much skills training programmes as I can. Learning about tips on how to reduce poverty in households like having vegetable gardens helps a lot. Other families do take on the suggestions and things really do become better for them as there is food for them”.

Participant H: “I am always motivated by the love I have for children and the determination to help all those in need.

Some caregivers relied on fate, religiosity and dependency on others to help them cope. Some caregivers found that prayer gave them the strength to deal with the difficulties of their work. Those caregivers who were more dependent on external coping strategies placed pressure on themselves to make the working environment conducive for themselves and their clients. As a result these caregivers experience more emotional and health difficulties than those caregivers who make use of internal ways of coping.

Participant C: “The only way to survive in the work I do and my source of strength is prayer”.

Participant F: “For as long as I worked I cope by learning from others and maybe getting insight from workshops. This is what makes me feel strong at work and makes me know my work”.

One of the caregivers made use of a coping strategy that combines elements of personal strategy as well as relying on fate.

Participant E: "It is in telling me that I want to be a caregiver and I want to do this work. Also if things could change and there be good working relationships; I would enjoy my work a lot and do more than I can".

4.4 Summary

This chapter discussed the psychological impact of caregiving on non-professional caregivers through the discussion of four themes. These themes were based on the information contained in the participants' interviews. The identified themes were poverty as a cause of psychological distress; overwhelming nature of the work; the need for support structures for caregivers; and coping and the psychological well-being of caregiver.

The discussion also highlighted sub-themes within these four major themes. The discussion of the themes included direct quotes from the participants' accounts in order to provide evidence of the themes. In the following chapter the fundamental findings of the thesis are discussed with reference to the theoretical background and results of the research.

CHAPTER 5

DISCUSSION

5.1 Introduction

This chapter discusses the research findings presented in chapter 4's potential to help caregivers of HIV/AIDS orphans. The findings are discussed in relation to the theoretical background used for this research.

5.2 Theoretical implications

Chapter 2 contained an overview of General Systems Theory. This theory was used because HIV/AIDS does not occur in isolation but exists within a wider socio-economic context that deepens the vulnerability of households, communities and nations. The involvement of caregivers in this field thus occurs within a broader context of living.

General Systems Theory can be viewed as a general science of wholeness (Bertalanffy, 1968) that aims to understand and investigate the world as sets of systems. The caregivers of HIV/AIDS orphans and other children affected by HIV and AIDS can be seen as a system. This system consists of diverse people working together to direct their specialized capabilities towards achieving common goals for their clients.

Pidwirny (2006) identified several characteristics that are shared by most systems. According to Pidwirny (2006) systems:

1. have structures that are defined by their parts and processes;
2. are generalisations of reality;
3. consist of various parts that have functional as well as structural functioning between them;
4. are able to exchange information with the outside environment; and
5. consist of parts that that show some degree of integration and work well together.

Based on these characteristics of a system, it is possible to state that caregivers function within a larger system to give service and care to the community. If the caregivers are to fulfil this role they need to be supported by the larger system, which consists of their supervisors and managers within the organisation. Failure in any of the relationships can potentially jeopardise the functioning of the system.

Caregivers and their managers have to be able to make adjustments based on the feedback they receive from their interactions with their clients and other organisations. These adjustments help maintain the stability of the system. If the system is not stable the caregivers are likely to be unable to cope with their work.

Caregivers of HIV/AIDS orphans are therefore influenced by multiple interactions and not only by their interactions with the HIV/AIDS orphans and their families. These volunteers

have a purpose or goal within their broader community to serve and ensure a better life for their nation. The caregivers' psychological well-being is therefore not only affected by their relationships with their patients but by the broader system in which they exist. This system includes their relationship with their superiors as well as their relationships with various people from within the health and social governmental organisations or structures.



Figure 1. Systems Thinking in Employee Relations

Source: Serrano, G. (2009 p. 26).

Figure 1 illustrates the importance of wholeness within systems theory (Serrano, 2009). Each part of a system must be seen in relation to the overall system and not in isolation.

In the section below the research findings concerning the caregivers' experiences are discussed in relation to the impact on the caregivers' psychological well-being.

5.3 Discussion of the findings

5.3.1 Poverty as cause of distress

The caregivers highlighted poverty as a major cause of distress affecting their clients as well as their own emotional and physical well-being. None of the participants in the study was employed and therefore the participants were solely reliant on incentives received for caregiving. The caregivers found working and living in a poverty stricken environment to be unpleasant and disheartening.

According to the caregivers their clients experience a lot of grief and sorrow as a result of poverty. Caregivers experienced suffering and heartache as a result of their clients' sorrow. Most of the caregivers were overwhelmed with feelings of helplessness, guilt, and suffering in situations where they were unable to assist their clients. Some of the caregivers were able to manage these feelings by acknowledging their own efforts in relation to ensuring their clients' survival and well-being.

The caregivers feel that they need to continue to fight against poverty. The caregivers are dependent on the organisation for financial security and view financial security as a rare resource that is necessary for their survival. Although the caregivers are committed to their clients and work hard to insulate them from poverty and hunger they remain dependent on external structures to assist them in obtaining government grants and securing their clients' well-being. These external structures include social welfare, the Department of Home Affairs,

and various medical practitioners. The caregivers experience immense emotional toil as a result of unproductive working relationships with these external structures and unsuccessful applications for children's grants. The caregivers experience feelings of anger, unhappiness, distress and sorrow as a result of these difficulties.

The caregivers' observations in this research study are similar to the findings presented by Uys (2002), who reported that economic constraints are a serious challenge for caregivers working in the field of HIV/AIDS. Various other researchers, including Lehmann and Zulu (2005), UNAIDS (2000), Hlabyago and Ogunbanjo (2009), and Tladi (2006), have also emphasised the devastating effects that poverty has on caregivers in the HIV/AIDS field.

5.3.2 Overwhelming nature of work

The results of this research study clearly illustrate that caregivers of HIV/AIDS orphans and children affected by HIV/AIDS experience work overload. They experience emotional and physical symptoms as a result of the wide-ranging duties they have to perform on a daily basis in order to ensure the survival and well-being of their clients. The devastating deaths and illnesses that result from HIV/AIDS place a lot of pressure on the caregivers to be responsible for their clients' health and survival, as well as their emotional and psycho-social needs. In addition, the caregiving duties frequently extend to include the children's families and this places added strain on the caregivers.

The caregivers indicated that the clients' family members need to share in the burden of care. Caregivers experience frustration, a desire to give up, and lack of motivation due to the overwhelming nature of their job and the lack of assistance received. Caregivers require unity and good working relationships if they are to be empowered to overcome the challenges of

working as a caregiver.

Caregivers also require assistance and co-operation from their supervisors as well as various governmental departments. Honest, open, and supportive communication is essential to successfully handling the day to day problems impacting HIV/AIDS orphans. However, the caregivers' discussions made it clear that this kind of working relationship is still a long way from being a reality.

The caregivers highlighted negativity from their superiors about their work, minimal open communication, and strained relations between them and the governmental departments as sources of stress and depression. Cases that remain unattended for long periods, lack of appropriate documentation and misinformation from the social departments all hinder the caregivers' attempts to provide a better life for their clients. These factors contribute to the caregivers' feelings of despair.

The Health Systems Trust Report (2004) indicated that South Africa's child welfare system is under extreme pressure due to the increasing number of children orphaned by HIV/AIDS. This resulted in the foster care system being overwhelmed and many AIDS orphans being left stranded. This contributed to some of the caregivers experiencing difficulties in coping and adjusting to the difficulties faced by the system.

In addition to reporting emotional symptoms related to stress a number of the caregivers also reported experiencing physical symptoms of stress. These symptoms included headaches, loss of appetite, insomnia, and exhaustion. These symptoms are also indicative of the impact that working in this field has on their psychological well-being.

The caregivers' emotional involvement with their clients also contributed to their feelings of being overwhelmed by their field of work. The caregivers all indicated that they are emotionally involved with their clients and some of the caregivers indicated that this involvement has a negative impact on them. These caregivers over identified with their clients and experienced the same pain and suffering as their clients. This over identification resulted in these caregivers experiencing extremely high levels of distress. They place themselves under a lot of pressure to overcompensate for the poverty in the lives of their clients. This results in feelings of disappointment and hopelessness when they are unable to meet their clients' needs.

Held and Brann (2007) identified the emotional involvement of caregivers with their clients as a major source of stress. According to Edelman (2000) the length of time that the caregiver and recipient have known each other also impacts on the emotional involvement between them, with longer relationships leading to greater emotional involvement. Caregivers are likely to experience greater feelings of helplessness when confronted with desperate situations in relation to these clients.

The caregivers in this study indicated that working in a community that has been devastated by HIV/AIDS has a severe negative effect on them. They find it difficult to distance themselves from their clients' suffering and experience feelings of sadness and worry in relation to their clients.

A study by Shisana, Hall, Maluleke, Chauveau and Schwabe (2004) found that many African caregivers identify with their clients because either they or their loved ones are also infected

with HIV. According to Miller (2000) this self-identification with patients is a major factor contributing to occupational stress and burnout among AIDS caregivers.

5.3.3 Support structures for the caregivers

Support is vital in assisting the caregivers in coping with the overwhelming nature of their work. The caregivers in this study highlighted various methods of support that would assist them in becoming psychologically well-adjusted and effective caregivers. This study shows that support in various spheres, specifically emotional, psycho-social, economic, and external support, is a crucial factor in maintaining balance in the caregivers' psychological well-being.

Caregivers who received supported from their families and significant others expressed feelings of contentment. This support enabled them to continue working as caregivers. The emotional containment they receive from their families serves as a catalyst to uplift their spirits. In contrast, those caregivers who received no emotional support from their families experienced feelings of loneliness and distress and struggled to cope with the demands of the job.

In addition to emotional support the caregivers identified a need for financial security. The caregivers do not have access to economic resources and are forced to work with children from impoverished backgrounds, which results in the caregivers experiencing additional strain. The lack of financial stability results in the caregivers experiencing suffering and being unable to sustain their families' needs.

In addition to requiring financial security to meet their basic needs caregivers also require

financial stability in order to enable them to take care of their health. This is especially important for caregivers who are HIV positive and who require medical treatments. Providing caregivers with financial stability is the responsibility of the organisations as well as of governmental departments. These external structures need to ensure that the caregivers are well cared for and recognised for their work in this field.

Psycho-social support can also serve as a buffer against stress. Streeter and Franklin (1992) defined psycho-social support to be any form of support ranging from having informal conversation to formal meetings. A study by Maslanka (1996) concluded that support was the strongest variable influencing the efficacy and performance of HIV/AIDS volunteers. Although the caregivers in this study do rely on each other for support it was also clear that this support was not adequate. The caregivers all experience the stressful conditions differently. The emotional, physical and mental support they provide for each other may therefore not be adequate to address each caregiver's specific needs.

The lack of adequate support suggests that the caregivers are never really able to deal with the emotional and mental exhaustion and suffering and this is likely to result in burnout. The caregivers in this study indicated that they sometimes just try to push the negative thoughts away in order to get themselves through the day. Providing long term therapeutic interventions to the caregivers of HIV/AIDS orphans is important in order to ensure that they are equipped with appropriate coping skills.

Recognition and encouragement from both the management and clients is another source of crucial support. The caregivers in this study indicated a desire for their efforts to be appreciated by their superiors. When this appreciation and support is not forthcoming the

caregivers experience feelings of inadequacy, lack of accomplishment, demotivation, and a desire to give up. In order for the caregivers to experience a sense of self-worth and of value in their field of work it is important that they be recognized and appreciated by their superiors.

The caregivers also require support from their clients. Being appreciated by their client's helps caregivers cope with the demands placed on them. Caregivers become involved in this field because they want to help individuals affected by HIV/AIDS, they want to show their love for their fellow human beings and they want to function as parents to these orphaned children. Caregivers therefore become distraught when they do not seem to be fulfilling their roles in their environments. Being thanked or praised by their clients and seeing the effects of their hard work can help caregivers feel appreciated and needed. This helps them feel that their work as caregivers is important and necessary.

A study by Bennett et al. (1996) found that recognition and reward buffer against experiences that are perceived as stressful. The study also found that rewards in the form of gratitude from clients and recognition and support from management positively influenced the organisational climate. An earlier study by Bennett et al. (1994b) highlighted the importance of social recognition and reward in promoting psychological well-being and quality of life in caregivers.

Caregivers can also receive support from management in the form of informational support. Informal caregivers in the field of HIV/AIDS take on their duties without any formal training or learning. Knowledge and further training in the field can play a pivotal role in managing and decreasing the stress experienced by the caregivers as it will equip them to handle

various difficulties. This support can be provided by creating opportunities for caregivers to attend more counselling courses, holding workshops related to their field of work, providing skills training courses, and providing mentoring from their superiors. Most of the caregivers in this study expressed a need for more formal training in order to empower them to deal with the issues they encounter. This training would also play a role in the caregivers' personal growth as it would help them feel more adequate in their work.

These support structures also help caregivers cope with the impact of caring for HIV/AIDS orphans and vulnerable children. Coping enables the caregivers to adjust to and understand their working conditions, thus enabling them to learn to manage their tasks and roles. Effective use of the coping style described by Bennett and Kelaher (1993) may translate to a greater sense of control over work-related stressors. From a systemic point of view it becomes apparent that caregivers do not work in isolation. Different economic supportive structures, role played by management, colleague support, and client support are important and needed for the caregivers to cope well in their field of work.

5.3.4 Coping

Having good coping skills is important when working in the field of HIV/AIDS. Adapting to these difficult working conditions and managing the challenges and stressors involved with working with clients on a daily basis is dependent on having the correct coping skills and access to appropriate support structures. The results of this study suggest that the caregivers' coping styles vary greatly. Some of the caregivers indicated that they do not cope very well at work while other caregivers stated that they cope well at work. Caregivers who reported developing a personal coping style that supports his or her physical, emotional, and mental

limits were able to cope well. In contrast, caregivers who had not developed a personal coping style struggled to cope.

Lazarus and Folkman (1984) suggested that there needs to be a fit between the coping strategy used by the person and the anticipated problem or stressor. According to this model people experience difficulties when they try to use a problem-focused coping style (internal coping) when dealing with problems they cannot change. In addition, people who use an emotional-focused coping style (external coping) can be as frustrated if dealing with problems that can be changed.

The results of this study indicate that some of the caregivers still need to learn how to use different coping skills in different circumstances. According to Bennett and Kelaher (1993) external coping style use combined with age and the number of hours spent on work is predictive of burnout.

In this study various caregivers, both young and old, mentioned being unable to cope in the field and experiencing feelings of emotional, physical and mental exhaustion. Some caregivers indicated that they were able to spend quality time with their families and significant others while some of the other caregivers found that they were not able to spend quality time with their families due to mental and emotional exhaustion. These results indicate that the personal style of coping and ways of dealing with problems and adjusting to the conditions at work are crucial for the well-being of the caregiver.

Within this study the caregivers who employed internal coping styles and believed that they had the ability to influence events and the environment were able to cope well. These caregivers were able to be assertive and make decisions without their supervisors' guidelines. They were also able to understand and accept their own limitations in terms of the care they can provide for their clients.

Caregivers who relied on external coping strategies such as fate or prayer were not able to distance themselves from their clients' suffering and experienced higher levels of distress than their colleagues. These caregivers were also unable to cope with various work related issues. These findings echo the findings reported by Krause and Stryker (1984), who suggested that individuals who believe they have some control over their own lives cope more effectively with stress. The caregivers in this study could benefit from having more knowledge and educational interventions regarding coping techniques as this would enable them to function optimally and use effective coping techniques.

5.4 Conclusion

In this chapter the impact of caregiving on caregivers of HIV/AIDS orphans and children affected by HIV/AIDS was discussed. The discussion was based on the theoretical background of the research project and on the themes identified during the data analysis phase.

A General Systems Theory framework was used in an attempt to view the experiences of the caregivers as part of a broader systemic context. The caregivers were thus seen as part of larger systems that they influenced and that influence them.

The results of the analysis clearly indicate that poverty and poor economic resources are the major stressors in the field of HIV/AIDS. The caregivers come from impoverished backgrounds and are therefore familiar with the devastating effects of poverty. This results in the caregivers becoming emotionally, physically, and mentally overwhelmed. The caregivers also experience a lot of strain and stress as a result of their heavy workloads. The results of the research suggest that the caregivers require support from their families, governmental structures and organisational management in order to cope with their duties and function effectively.

The findings also indicate that caregivers require emotional support from their significant others, psycho-social support from the various systems with which they interact, economic support, and external support in order to ensure their survival in the field of HIV and AIDS. When these supportive structures are absent the caregivers become overwhelmed and their psychological well-being is negatively influenced.

The ability to cope within the field of HIV/AIDS is crucially important as it contributes to the caregivers' emotional, mental and behavioural adjustment. Failure to make use of effective coping mechanisms can have detrimental effects on the caregivers' well-being. The

caregivers in this study reported experiencing negative emotional feelings as well as physical symptoms related to stress.

The findings of this research can be used to make a number of recommendations and suggestions regarding future HIV/AIDS interventions. These recommendations and suggestions are discussed in the final chapter.

Chapter 6

Summary, recommendations and conclusions

6.1. Introduction

Since the outbreak of the HIV/AIDS pandemic the mortality rate has increased dramatically, leading to an increase in the number of HIV/AIDS orphans. HIV/AIDS has led to the loss of primary caregivers and the weakening of traditional networks and this has created a need for nonprofessional caregivers in the field of HIV/AIDS. These caregivers play a vital role in providing for the psycho-social and emotional needs of HIV/AIDS orphans.

These caregivers care for the HIV/AIDS orphans. In addition, they support and protect HIV/AIDS orphans and children affected by HIV and AIDS from various risks and problems encountered by these children as a result of the pandemic. The caregivers' task is to ensure optimal growth and success in the lives of the AIDS orphans and other children affected by HIV/AIDS. This study investigated the impact that these tasks and responsibilities have on the caregivers' psychological well-being.

6.2. Summary of the research study

Chapter 2 outlined the General Systems Theory framework used in this study. General Systems Theory takes into account numerous systems that interact with other systems for their sustained existence and seeks to arrive at a holistic view of a phenomenon (Covington, 1998). Within this research study the organisation and the participants studied were viewed as a system existing within the larger context of HIV/AIDS.

The system described in this study is an open system in that it permits working relationships

amongst caregivers and their patients that involve an interchange of behavior and emotions. There is also constant interaction with other outside structures or organisations such as schools, communities, and organisations. These organisations provide support for caregivers by keeping them informed and educated concerning the roles of being caregivers. This results in a skills transfer that ensures sustainability and continuation of service delivery.

The chapter also looked at the demographic characteristics of caregivers of HIV/AIDS orphans and children affected by HIV and AIDS. The discussion found that the burden of care is usually borne by women and young girls and that this results in women and their families being more likely to be malnourished, in poor health, or economically destitute (UNAIDS, 2006). However, recent research suggests that a small but significant number of men are increasingly involved in caregiving responsibilities.

The chapter then focused on the stressors that may impact the caregivers and on coping mechanisms to manage these stressors. Caregivers caring for HIV/AIDS orphans may experience stress for a variety of reasons, including financial hardships, work overload, lack of support and recognition, lack of skills and over involvement with the recipients of care.

According to Armstrong (2000) much of the stress experienced by caregivers in the field of HIV/AIDS as related to the nature of the work itself; the fact that they are dealing with an incurable condition that kills largely young people, causes terrible suffering and is heavily stigmatized. In order to cope with their demanding and threatening work environment caregivers must have effective coping strategies and must employ these coping strategies in an attempt to manage and adjust to the stressful event. Various social, economic, psycho-social and external supports also play a vital role in assisting caregivers in coping within the

HIV/AIDS field.

Chapter 3 described the phenomenological research approach used in the study. The phenomenological approach is based in a paradigm of personal knowledge and subjectivity, and emphasizes the importance of personal perspective and interpretation. This approach was chosen as it enabled the researcher to explore the aims and the objectives of the study. The study also made use of a qualitative research method as a means of gathering data. Qualitative research designs allow the researcher to gain in-depth and detailed information concerning the phenomenon of interest. A semi-structured method of data collection, involving the use of in-depth semi-structured interviews, was employed to explore the phenomenon.

Eight informal caregivers participated in the study. The participants were selected from the Khanyiselani Development Trust drop-in care centre. One of the caregivers was male while the rest of the caregivers were female. Participants' ages ranged between 26 and 46 years old. All participants work in a caregiving role towards orphans of HIV/AIDS and other children made vulnerable by HIV/AIDS. The children they work with are all aged between 0 and 17 years old. The caregivers had various levels of experience of working as caregivers, ranging from one year to seven years' experience.

Permission to access the participants at Khanyiselani community based care centre was granted by the founder of the Khanyiselani development trust. Written consent concerning the purpose of the research, the expectations of the research participant, the voluntary nature of the research and the confidentiality of the research was obtained. The name and contact information of the local lead investigator was also provided and participants were encouraged

to contact this investigator if they had any questions or problems. Data was then analyzed using an interpretive analysis approach. The research themes were presented in chapter 4.

The research findings were discussed in chapter 5. The psychological impact of caring on the informal caregivers was interpreted and presented in accordance with four major themes. These themes were poverty as a cause of psychological distress, overwhelming nature of the work, the need of support structures for caregivers, and coping and the psychological well-being of caregiver.

The findings of the investigation provided insight into the experiences of the caregivers and the impact of caregiving on their psychological well-being. The caregivers reported that poverty was a major cause of distress and impacted both their clients' and their own well-being. The caregivers participating in the study were unemployed and relied for financial security on incentives received for being caregivers. The caregivers highlighted that working and living in a poverty stricken environment is unpleasant. They stated that their clients experience a lot of grief and sorrow as a result of poverty. Caregivers experience suffering and heartache as a result of witnessing their clients' suffering.

Further adding to the distress on the caregivers is the emotional attachment to their clients. Feelings of helplessness, hopelessness, despair, disappointment, and responsibility are some of the emotional conflict experienced by the caregivers due to their emotional involvement with their clients. The caregivers mentioned internalizing their client's pain and suffering resulting in the caregiver feeling obligated in being responsible for the client's life, wellbeing and survival. This however seems to cause a turmoil of emotions on the caregiver, especially when they feel as though they are failing the client.

Another important aspect relayed by the caregivers regarding their work is the need of supportive structures in their domain. This according to the caregivers is a need in alleviating the overwhelming nature and demand of their work. Seemingly the different methods of support identified by the caregivers are for the sole purpose of becoming psychologically well-adjusted and effective caregivers.

Emotional support whether received from the significant others, employers, clients or counselors is very significant for the caregiver's personal and emotional development as well as stability as a human being. In a similar view economic and external support is vital for the gain of personal accomplishment desired by the caregiver in order to feel effective and adequate in the field thus enhancing their self-concept. Positive reports of caregiving, rewards and recognition of the important role caregivers play seemingly were mentioned by the caregivers as a positive aspect of their wellbeing in the working environment.

Lastly coping was understood in the field of caregiving as a way of being able to adjust to stressful situations; a sense by which one is able to tolerate stressful situations; and by means of effective strategies having solutions of dealing with the situation. Having and employing effective coping strategies may result in psychologically adjusted caregiver.

6.3 Limitations and implications for future research

One of the main limitations of this study involves the small sample size, which included only eight participants from the same organisation in Kokstad, Kwa-Zulu Natal. A further limitation of the study relates to the inclusion of only one male participant, which might be indicative of an underrepresentation of male caregivers. A Larger scale study would have allowed for more generalizable findings.

It is recommended that future research efforts in this area include a larger number of participants from a wider geographic area in order to broaden the understanding of the phenomenon. It is further recommended that future studies include more male participants, in order to investigate the experiences of male caregivers of HIV/AIDS orphans and children affected by HIV/AIDS.

This study has made a valuable contribution to knowledge by allowing the silenced voices of the caregivers in this particular geographic area to be heard. Addressing the concerns highlighted above will help in designing appropriate supportive programs that will meet the needs of the caregivers. In addition the systemic approach showed that it can be a valuable framework in researching the different and unique individual experiences whose phenomena about the world do not occur in isolation but is shaped by the environments and interactions within they exist.

6.4 Recommendations

The results of this study show that many households are adversely affected by poverty and that the presence of HIV/AIDS results in a further depletion of income. Programmes such as the food parcel programme and the soup kitchen programme are extremely beneficial to the clients. These programmes help to reduce the care burden placed on the caregivers. It is important that the organisations involved in these food programmes maintain open communication with the caregiving groups.

The available support structures need to be maintained on a regular basis. It is recommended that caregivers take the initiative in structuring groups by involving their clients and initiating

projects such as vegetable gardens and art work as a means of increasing their income-generative opportunities.

However, simply supplying financial assistance to caregivers is not sufficient. Caregivers also require emotional support and this can be achieved by providing a therapeutic space in which the caregivers are able to discuss the stressors inherent in their work and strengthen their abilities to cope with these stressors.

Emotional support is also vital for the optimal functioning of the caregiver and to ensure sound psychological functioning. It is recommended that caregivers be provided with therapeutic support groups to assist them in attaining optimal emotional functioning. Dependent on the availability of resources it is further recommended that counselling be prioritised in future plans. This can be achieved by having at least one counselor available to caregivers at specific times.

Open communication between caregivers and superiors is important in ensuring the optimal functioning of caregivers. Caregivers need to feel that they are part of the larger organisation and that their needs and concerns are recognized and addressed.

Finally, caregivers must have a clear understanding of their duties and the limits of their responsibility for any client. It is recommended that education and training programmes concerning their role be offered to caregivers. These programmes will equip them with knowledge regarding how to handle the challenges they encounter and also enable them to feel self-assured about themselves and their roles, thus enhancing their self-concept.

6.5 Conclusion

This study aimed to assess the psychological impact of caring on caregivers of HIV/AIDS orphans. The study aimed to access the caregivers' subjective experiences and perceptions of their caregiving roles. The study made use of a semi-structured questionnaire as a method of data collection, using in-depth interviews to explore the phenomenon.

The results of study indicate that caring for HIV/AIDS orphans can be emotionally, mentally and physically challenging. In addition, the existence of internal and external supportive environments can help ease the burden of caregiving on caregivers. The study adds to the body of knowledge in the field of HIV/AIDS and seeks to inform policies and organisations.

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APPENDIX A

INTERVIEW GUIDE

A. Demographic data

Date of birth

Age

Gender

Marital status

Ethnic group

Highest level of education

Home language

Number of dependants in the household

Type of work participant does

Age of clients you work with

Duration of working as a caregiver

Previous employment history

Any training received

B. Interview questions

i. Caregiver experiences

- What motivates participant to be a caregiver for HIV/AIDS orphans and other vulnerable children affected by HIV/AIDS?
 - How often do you work with your clients?
 - Do you work with children with HIV infections or AIDS?
 - What are the stressors or difficulties encountered in the caregiving role?
 - Have you felt responsible for the pain and suffering of the children in your care?
 - Are there times where you feel frustrated when there is little you can do to help the children under your care?
 - Have you ever had fears of being infected while offering your help to your clients, and if yes, how do you deal with those fears?
 - Do you feel that you are adequately trained for your role as a HIV/AIDS orphan and other vulnerable children's caregiver?
- ii. Support systems available for caregivers
- Do you have any source of support? If yes, from where do you receive this support from?
 - How helpful is it to you to receive support (this can be family; work; or any other form of support)?
- iii. Coping as a caregiver
- Is the amount of time spent in the field and time spent with significant others balanced?
 - What are your coping mechanisms in dealing with the challenges you experience as a caregiver of HIV/AIDS orphans and other children made vulnerable by HIV/AIDS?
 - What are your most important needs that could help alleviate stress and in managing the work involved with being a caregiver?

iv. Signs of stress

- Do you experience any physical problems (such as headaches and pains, exhaustion, difficulty sleeping) and emotional difficulties (such as being easily tearful, marked sadness, discouragement) as a result of your work?
- Are the above physical and emotional symptoms occurring often or less often?
- What do you do when you experience the above symptoms often?
- Do you find yourself more concerned or attached to certain children than others? If so why do you think this is?
- Does this affect your caregiving role and responsibilities in any way?

APPENDIX B

To whom it may concern as research participant

Dear Participant

I am Valencia Veliswa Guqa. I am currently registered at the University of South Africa (UNISA) for a Masters Degree within the Department of Psychology. I am interested in doing a study on the Psychological impact of providing care to children orphaned by HIV/AIDS. The aim of the study is to capture the lived experiences of caring for HIV/AIDS orphans as well as the impact thereof. This study can be successful with your participation and hence your contributions will be highly appreciated.

The following will apply should you agree to partake in the study:

- 1) Your participation is voluntarily. Should you feel the need to withdraw from the study, permission to discontinue is granted.
- 2) The interview will be conducted with respect for your privacy.
- 3) The information obtained will be used for research purposes only. All information received from the study will be treated with confidentiality.
- 4) Your identity will be kept anonymous thus there will be no mention of your name to anyone or in the research transcripts.
- 5) The interview will be audio-recorded for analysis purposes and all information will be kept secure by the researcher at all times.

Thank you for your participation.

Valencia Veliswa Guqa

APPENDIX C

Isazisi Sesivumelwano

Mna (igama) ndiyavumelana noku
kulandelayo:

- Ndinika imvume yokuba lonke ulwazi endinalo ngam nomsebenzi wam kungasetyenziselwa uphando. Intsebenziswano yam yonke isekubeni konke okuthethwayo kuzoba mayelana nophando kwaye isazisi sam sizobayimfihlo. (Tick)

- Andinanxa nokuphendula imibuzo ebuzwayo futhi nayiphi na into emayelana nalolu phando nje ngokulandelayo:

Audio taping

Signed: _____ Date: _____

Inggina: _____ Date: _____

Appendix C

Informed consent

I (name) agree to the following:

I give consent that all information regarding my work and I be used for the purposes of the research. My participation is provided that my confidentiality and anonymity is assured.

I have no problem in answering any questions relevant to the research as well as the usage of research tool such as the following:

Audio taping.

Signed: _____ Date: _____

Witness: _____ Date: _____