

**THE EXPERIENCES AND COPING STRATEGIES
OF HIV/AIDS PRIMARY CAREGIVERS WITHIN
TWO DISADVANTAGED COMMUNITIES IN THE
WESTERN CAPE METROPOLE.**

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Acquired Immuno-Deficiency Syndrome

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Phenomenology

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ABSTRACT

The Human Immuno-deficiency Virus (HIV) that leads to Acquired Immuno-Deficiency Syndrome (AIDS) is considered to be spreading at a high rate in South Africa. Research indicates that this disease is highly prevalent among people aged between 15 and 49. It is estimated that one in five adults in South Africa is HIV positive. According to the World Health Organisation (WHO), HIV/AIDS presents itself in four stages. During Stage I and Stage II individuals are asymptomatic and thus functional. In stage III and Stage IV, sufferers experience debilitating opportunistic infections, therefore requiring emotional, financial, physical and social assistance. Community or home-based care nurses manage the treatment of sufferers at their homes while under the care of their family members, friends, spouses and significant others. Caring for an HIV+ person can be very demanding, impacting on carers financially, physically, emotionally and socially. The present study explored the experiences and coping strategies of HIV/AIDS primary caregivers. Eight (8) participants, consisting of both males and females aged between 20 and 44, were drawn from two disadvantaged communities in the Western Cape Metropole, namely Guguletu and Khayelitsha. The study adopted a phenomenological method of enquiry given the paucity of qualitative, interview-based research on HIV/AIDS caregivers. The results of the study revealed three dominant components of the caring experience, namely: 'The Caring Experience', 'Family and Community Responses', and 'Managing the Role of Caring and the Societal Response'. It was found that caring for an HIV infected individual is emotionally and financially taxing for the carer. Families and community were also observed by carers to be emotionally strained by the HIV diagnoses of their loved ones. The researcher recommends that advanced training for HIV/AIDS formal caregivers is needed to enable them to assess stress among the informal caregivers and to enable them to refer accordingly.

DECLARATION

I declare that *The Experiences and Coping Strategies of HIV/AIDS Primary Caregivers Within Two Disadvantaged Communities in the Western Cape Metropole* is my own work, that it has not been submitted for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

Full name..... Date.....

Signed.....

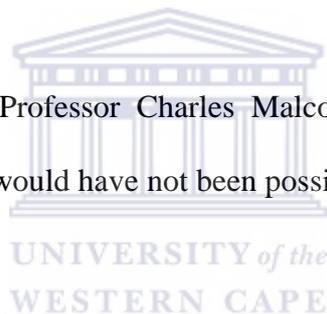


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Firstly I wish to thank all the caregivers who agreed to participate in this study, for being able to share their experiences, which can be a very difficult part of their lives. My greatest sympathy to those that have lost their loved ones during the research process. May their soul rest in peace.

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To my family, especially my brothers and my husband, a great thank you for their constant support, encouragement as well as understanding.

CHAPTER ONE

INTRODUCTION

1.1 Introduction to the Study

The present study focuses on the experiences and coping strategies of primary caregivers caring for HIV/AIDS sufferers at home in two communities within the Western Cape Metropole.

The Human Immuno-deficiency Virus (HIV) continues to spread across the world, strengthening its grip on adults and moving into communities previously little troubled by the epidemic. With regard to the prevalence of this disease, recent studies indicate that South Africa has one of the highest rates within Sub-Saharan Africa (Ala, 2001). It is estimated that one out of every five adults in South Africa is HIV positive and that out of a population of 40 million, 4.2 million are currently living with the virus (Ala, 2001). The Western Cape was previously considered to be the province with the lowest HIV prevalence in the country. In a report compiled by the Western Cape AIDS programme in 2002 - based on a survey conducted on HIV prevalence within this province - it was found that the statistics had increased from 8.6% in 2001 to 12.4% in 2002 (Caelers, 2003). These figures were based on prevalence rates in pregnant women tested for HIV in the prevention of Mother to Child Transmission (pMTCT) programme taking place at the antenatal care settings at the state clinics within the province.

This study is based in two disadvantaged communities of the Western Cape; namely Gugulethu and Khayelitsha. These are the biggest townships within the Cape Metropole and both are overwhelmed by the HIV pandemic. Statistics in 2002

revealed that the prevalence of HIV cases among pregnant women amounted to 24.9% in Khayelitsha while the Guguletu/Nyanga area was found to be 27.8%. This is in comparison to the 2001 statistics that indicated 22% and 16.1% respectively (Caelters, 2003). These communities are not only disadvantaged by HIV incidence of epidemic proportions, but also have many squatter camps, severe overcrowding, and high rates of unemployment, contributing to poor socio-economic status.

1.2 Rationale and Motivation for the Study

The HIV pandemic is overwhelming public hospital capacities. A serious consequence of this being that other patients' care is compromised due to premature discharges from hospitals. The increased demands placed on medical budgets, combined with the prolonging of patients' lives through antiretroviral therapy treatment, has led to HIV being classified as a chronic disease best suited for home-based care (Hickey, 2001). It has been proposed that family members and others willing to care for the HIV/AIDS sufferers be given the opportunity to minimise the financial costs of the disease as well as to let sufferers die comfortably among their loved ones. This could also provide HIV infected persons with improved social support.

Home-care programmes were started in North America and Europe when it was found that families had difficulty coping on their own with the demands of caring for people living with HIV/AIDS (PLWHA) (Spier & Edwards, 1990 in Uys, 2003). During the late 1980s and early 1990s this type of service was introduced in a number of African countries (Sims & Moss, 1995 in Uys, 2001). In South Africa, hospices and community-based care organizations have been designed to take care of those that are

infected with as well as affected by HIV-related illnesses. Although these facilities are available, hospices can only offer respite for family/friend caregivers for a period of two weeks (St. Luke's Hospice website). In severe cases, sufferers are taken in for symptom control until the opportunistic infections are manageable. Home-based care entails the provision of necessary health care by a volunteer caregiver to a patient or family at home, often with the support of a Community Caregiver. These support services are offered by Community-Based Organizations and include home visits, where assistance is given with physical, medical, and emotional care. This, however, can only be done for a limited number of hours per week due to the number of patients allocated to a volunteer worker in a specific area.

Carers working in these organizations have undergone training in home-based care. This is offered for a period of one to six months, the course length differing from training institution to institution. In a study conducted by Uys (2001), community caregivers from seven sites that participated in the study had been trained for three months in the theory and practice of home-based HIV/AIDS care. Unlike family/primary caregivers, community-based caregivers receive emotional care from the institutions that employ them.

Although the services of community-based caregivers are available, it is the informal caregivers who provide most of the care for the sufferers. Thus they experience a lot of emotional, financial, physical and social difficulty. These people are typically the lovers, spouses, children, friends or family of someone diagnosed with HIV/AIDS. They usually have little or no training in the home-based care which is offered to

them by community caregivers during visits, which would enable them to cope on their own when these professionals are not present.

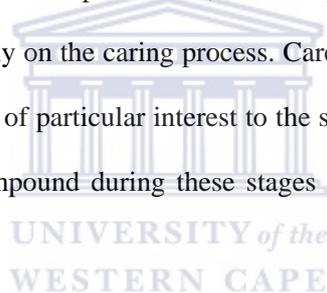
The primary caregivers provide practical support (e.g. shopping, housekeeping, bathing, feeding, etc.) and as symptoms worsen they are likely to take on more clinical roles such as keeping track of medication, giving injections, inserting catheters and cleaning wounds (Folkman et al., 1994). In many cases the caregiver finds him/herself caring for more than one person. Unlike formal caregivers and volunteers, these people are on call 24 hrs a day, thus they are faced with many challenges. Caring not only increases the financial burden on these carers (Ala, 2001), but it also produces the additional strain of stigmatisation (Powell-Cope & Brown, 1992; Turner, Catania & Gagnon, 1994), as well as distressing emotions, relationship difficulties, somatic symptoms and grief (Pakenham, Dadds & Terry, 1995).

Limited research has been conducted on the experiences of primary caregivers of HIV/AIDS patients. Moreover, the focus of the past research has been primarily on the role and experiences of formal caregivers, that is; doctors, nurses, volunteers, etcetera (Catalan et al., 1996; Dorz et al., 2003; Karasz, Dysche & Selwyn, 2003) and experiences of people living with HIV/AIDS (Chisholm & Grindel, 1998; Dunkel-Schetter & Kemeny, 1994; Hsiung & Thomas, 2001). Little attention has been given to the experiences of primary caregivers. The limited research sourced on informal caregivers was also mostly based abroad (Bor, 1990; Brouwer et al., 2000; Flaskerud & Tabora, 1998; Folkman, 1997; Hansell et al., 1999; Mullan, 1998; Pakenham, Dadds & Terry, 1995; Powell-Cope & Brown, 1992; Rose & Clark-Alexander, 1999; Turner, Catania & Gagnon, 1994; Turner & Catania, 1997) with some of these studies

looking at a specific group of people, for example; caregivers of positive children or gay communities (Brouwer et al., 2000; Folkman, 1997; Folkman et al., 1994).

In the South African context, research has addressed the burden of caring and the coping strategies of volunteers and home-based care workers (Melnick, 2002; Van Wyk, 2002), thus leaving room for the kind of research undertaken in this thesis. All these studies identified difficulties associated with caregiving in HIV/AIDS, but to date the effect of caregiving by a young adult to an infected young adult has not been looked at with specific reference to South Africa

The researcher based this research project in Gugulethu and Khayelitsha. As stated earlier in the Introduction, the two communities not only have a high prevalence of HIV, but are also overcrowded and impoverished, thus impacting emotionally, physically, socially and economically on the caring process. Caregivers of stage III to stage IV sufferers of HIV/AIDS are of particular interest to the study, as the demands placed upon them escalate and compound during these stages due to the decreased functionality of the sufferers.



1.2 The aim of the study

The aims of the study are:

- ◆ To explore the psychosocial experiences of HIV/AIDS primary caregivers.
- ◆ To understand the coping strategies employed by these caregivers to deal with their experiences and feelings, as well as the responses of the public towards them.

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Three main questions that this study attempts to answer are:

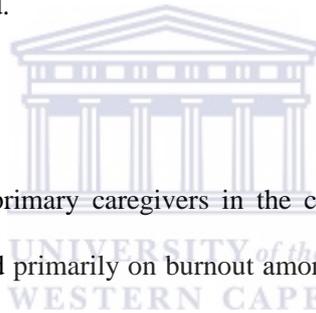
1. What are the experiences of caregivers living with and taking care of someone with HIV/AIDS?
2. How have others responded toward the caregivers knowing that they are caring for someone with HIV/AIDS?
3. How do caregivers deal with their experiences and in particular their feelings and the manner in which society responds to them?

The study lends itself to a phenomenological theoretical approach as it looks at experiences as expressed by participants. This study is located within a qualitative research paradigm. Participants were recruited through the St. Luke's Hospice Community-based Caregiver Programme and semi-structured phenomenological grounded interviews were conducted.

1.3 Significance of the study

Little research has been done on primary caregivers in the context of HIV/AIDS. Internationally, studies have focused primarily on burnout amongst formal caregivers (i.e. nurses, doctors, volunteers, etc.), (Catalan et al., 1996; Dorz et al., 2003). Other studies have focused on the coping mechanisms with reference to volunteers, as well as measures to enhance their coping skills (Hansell et al., 1999; Rose & Clark-Alexander, 1999).

In South Africa the same paucity of research in this area is found. The South African studies (Melnick, 2002 & Vanwyk, 2002) have focused on burnout, stress and coping mechanism amongst trained caregivers. Most of these studies are quantitative in



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nature. The aim of the present study is to address a gap in the field by exploring the experiences of primary caregivers, as well as the coping mechanisms employed by these individuals in the context of HIV/AIDS caregiving. This research is expected to provide valuable information that will enhance our understanding of the dynamics of living alongside and caring for an HIV/AIDS sufferer. The findings of this research are expected to not only inform interventions at the level of primary care, but also to impact on training programmes and policy formulation.

1.4 Key concepts clarification and abbreviations

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For the purpose of this study the following definitions and abbreviations will apply:

- ◆ **Primary caregivers:** An informal caregiver that may be a parent, grandparent, friend, spouse, lover, foster or adoptive parent, etc, who provides most of the care on a daily basis to the HIV/AIDS sufferer who is unable to provide for him/herself physically and emotionally. They do not have any formal training for caring. The words Informal Caregiver and Primary Caregiver later denoted as PCG will be interchangeably used throughout the thesis.
- ◆ **Caring:** The affective component of one's commitment to the welfare of another.
- ◆ **Young adult:** Defined as an individual aged from 20 to 39 (Siegelman & Shaffer, 1995), for the purpose of this study will refer to an individual aged from 20 to 44. Research has shown that people living with HIV/AIDS in sub-Saharan Africa are concentrated in the socially and economically productive groups aged 15-45 (HIV publications, 2005).

- ♦ **HIV:** Human Immuno-deficiency Virus
- ♦ **AIDS:** Acquired Immune Deficiency Syndrome caused by the HIV virus.
- ♦ **PLWHA:** People living with HIV and AIDS.

1.5 Thesis layout

Chapter One has presented the background to, rationale and motivation for the study, the aims of the study, and the significance of the study including clarification of key concepts with abbreviations. Chapter Two will examine the theoretical framework, the staging of the disease, the role of primary caregivers, and the relevant literature on experiences of caregivers, with regard to support and stigma and coping. Chapter Three will describe the research design and methodology. The research instrument, sample design, sampling technique, as well as the data collection process including data analysis procedures, will be discussed. Chapter Four will present and discuss the results. Finally, Chapter Five will give conclusions and recommendations.

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1.6 Summary

This chapter looks at the prevalence of HIV/AIDS in South Africa. It also gives the rationale for and background of the study. Arguments formulated by previous researchers are highlighted and the aims of the study are detailed together with the potential significance of the study. The researcher also gives clarity pertaining to operational concepts and abbreviations used within the study. The chapter ends with the detailing of the information to be discussed in following chapters.

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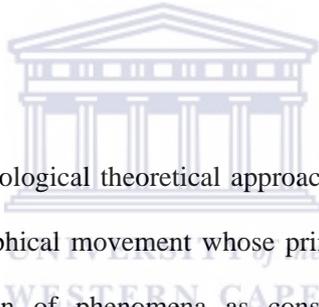
CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter begins by locating this research within a theoretical framework. The clinical staging of the disease is discussed to formulate an understanding of the disease process in order to clarify the challenges that a person caring for an infected person is faced at a given time. The role and characteristics of caregivers is then discussed in relation to what other researchers in the field of HIV/AIDS have observed. The literature review pertaining to experiences of caregivers- concerning their social support, stigma, and coping - is discussed to formulate arguments around the subject of interest. The chapter ends with a brief summary of the emerging issues related to the study.

2.2 Theoretical Framework



The study is located in a phenomenological theoretical approach. Phenomenology is defined as “the name for a philosophical movement whose primary objective is the direct investigation and description of phenomena as consciously experienced, without theories about their causal explanation and as free as possible from unexamined preconceptions and presuppositions” (Spiegelberg, 1970, p. 810). Wagner (1983 in Speziale & Carpenter, 2003) defines phenomenology as “a system of interpretation that helps us perceive and conceive ourselves, our contacts and interchanges with others, and everything else in the realm of our experiences in a variety of ways, including to describe a method as well as a philosophy or way of thinking” (p. 52). It also provides “a way of exploring lived experiences, the actuality of experiences, from the inside” (Osborne, 1994, p. 167).

This theory allows the researcher to explore how people experience, describe and interpret a phenomenon: In this case, living with and caring for PLWHA. Phenomenological research has been applied to several studies looking at caregivers caring for people with chronic diseases. Phenomenology allows the researcher to describe an individual's total sphere of experiences, which is bound by the objects, persons, and events encountered in the quest of realistic objectives of living. By exploring their experiences as well as their coping strategies, a description of the world as experienced by these participants will be given in order to discover the common meanings underlying the phenomena.

2.3 Clinical staging of HIV/AIDS

HIV/AIDS presents itself in many ways, and as the disease progresses through stages particular symptoms are normatively experienced by the sufferers at each stage. The World Health Organisation (hereafter referred to as WHO) classifies the progression of HIV/AIDS into four (4) clinical stages (Maartens, 1999). According to Maartens (1999) this presents a clear guide to the way this disease progresses. During Stage I, known as the early stage of the infection, the main symptom is swollen glands which persist. The infected person also presents with fever, headaches, tiredness, sore muscles and diarrhoea that occur for a few weeks to a few months after the infection (Maartens, 1999). Although the infected is experiencing these symptoms, these actually are minimal to the extent that the person appears asymptomatic. They are able to perform normal activities.

During Stage II of the infection, the infected person experiences repeated infections of the upper airways as well as mouth ulcers and less than 10% of unintentional body

weight loss. Other concurrent infections include shingles, rashes, skin diseases, fungal infections in the nail and severe cracks of the mouth. During this stage symptoms may be observable, but the individual can still perform normal daily activities.

The clinical features observable during Stage III are more than 10% of body weight loss, diarrhoea or fever that persist for longer than a month, thrush in the mouth, back of the throat and sometimes the female genitals, oral hairy leukoplakia, tuberculosis and pneumonia (Maartens, 1999). The sufferer is bedridden for less than 50% of the day, during the last month. All these indicate that AIDS will occur within a year or two (Maartens, 1999).

During Stage IV, also known as the AIDS-defining conditions, the infected presents with symptoms like wasting, chronic persistent diarrhoea for more than a month, affected brain functioning leading to confusion, with signs of mental disorder (Maartens, 1999). Other symptoms include opportunistic infections like tuberculosis in other parts of the body, pneumonia, herpes, fungal and parasitic infections throughout the body, infections in the brain and infections being carried around the body by the blood. Karposi sarcoma, which is a certain type of skin cancer, may also occur at this stage. The infected will be bedridden for more than 50% of the day during the last month thus requiring 100% nursing care. This stage can endure from anything from one (1) month to six (6) months so it may require more than short, acute periods of care.

The care given during Stages III and IV requires physical, psychological and social delivery of care, as sufferers are physically as well as mentally affected by the disease

leading to decreased functionality and independence. Therefore it is of great importance to the present study to assess the experiences and the coping strategies of the primary caregivers living with and caring for Stage III and IV HIV/AIDS sufferers at home.

2.4 The Role and Characteristics of HIV/AIDS Primary Caregivers

Primary caregivers are those individuals who provide practical help and nursing to PLWHA at home. Typically these individuals are parents, siblings, a partner or friend of the patient. These individuals have no formal training in caring for the terminally ill, yet provide physical and emotional nursing and financial assistance to PLWHA. In extreme cases, as is the case with Stages III and IV of the illness, these caregivers find themselves delivering services like bathing the patient, doing shopping for them, preparing meals, administering medication, and taking them for regular check-ups.

Turner, Catania and Gagnon (1994) conducted a study to identify the prevalence of informal AIDS caregivers in the United States, their social and demographic characteristics and the type of tasks they perform. It was noted that young adult caregivers (<40) suffer from the costs of lost opportunities as these individuals are striving to establish careers and economic security, developing stable relationships and entering the political and social life of the community. Caregiving imposes disruptions in task development on them, which might have detrimental long-term economic and psychosocial consequences. The current study looks at young adults of poor socio-economic status who find themselves in the arena of caring for their loved ones. Turner et al. (1994) also found that those with the poorest financial resources

are more likely to perform the most labor intensive care giving tasks due to their inability to pay for the professional services.

McCann and Wadsworth (1992) found that the majority of caregivers were friends and partners of PLWHA and the minority were siblings, volunteers and others. About 54% of carers were living separately from sufferers. Carers were performing tasks like personal and household chores, giving advice about health and welfare, providing psychological reassurance, and transporting and accompanying to appointments.

Primary caregivers are on call 24-hours a day. This is in contrast to nurses who are shift workers, thus having time off from patients. This in itself places great demands on the well being of the caregiver. Thorough research is therefore needed to advise on the needs of caregivers in order to develop interventions and support structures.

2.5 Literature Review

2.5.1 Previous Research on Caregiver Experiences

Little research has been conducted on caregivers of PLWHA. This is particularly needed with regard to primary caregivers since these people spend most of the time with the HIV sufferers. Formal training in caring for the terminally ill is minimal. This training is given by home-based carers who are themselves trained at a minimal level. For this reason, training usually focuses only on assistance with practical care. According to Mullan (1998), caregivers experience a lot of difficulties that have to do with patients' comfort; especially when patients are acutely ill or cognitively impaired. Secondary to that is interpersonal strain resulting from imbalances within the relationship when dealing with issues of autonomy, independence or reciprocity

(Mullan, 1998). The fear of the death of those they care for is a constant threat. These may result in feelings of “overload, of loss, of being a captive to caregiving demands, of guilt and of incompetence” (Mullan, 1998).

Feelings of loss do not only accompany/occur during the death of the care recipient. It is noted that chronic illnesses also give rise to longer periods of uncertainty resulting in what is termed anticipatory grief (Franklin et al., 1996). Anticipatory grief is associated with behaviours such as discussing the possibility of death, thinking what the future would be like without that person, discussing death with the person, adapting to role changes, changing assumptions, finding a balance for staying separate from and yet involved with the person, and experiencing feelings of sadness, depression and anxiety (Franklin et al., 1996; Keene Reder, 2003).

According to Edelman (2000), caregivers also experience feelings of poor self-esteem, stress, low morale, fatigue, anxiety and hopelessness about the future. Past psychiatric status, personality, social support networks, and the relationship of the carer and recipient, together with the nature of the illness and the degree of impairment, all are factors that aggravate the emotional experiences of caregivers (Edelman, 2000). The present study determines social support networks, the nature of the illness, and the degree of impairment as factors impacting the experiences and coping mechanisms of the caregivers with these emotions.

Brouwer et al. (2000) state that caregivers experience feelings of helplessness, denial and despair, and that this happens more often when the sufferer does not want to eat or respond to the services being rendered to him/her. Brouwer et al. (2000) also

observed that caregivers of HIV infected children became hopeless about the child's condition after learning the diagnosis. This led to decreased care, as they believed the child would ultimately die.

These experiences might also be noted with carers who are uninformed about the development of the disease. Due to a lack of information, caregivers might think that the sufferer is dying when the sufferers develop extensive pressure sores as a result of being bedridden, or become incontinent, confused or forgetful, or experience persistent nausea and vomiting. These conditions might bring feelings of uncertainty that in turn will exacerbate feelings of stress and low self-esteem among the caregivers.

It is also noted that poverty increases the worries of caregivers, as they might not have enough money for a balanced diet and regular medical check-ups, especially when the person is bedridden as there is a need for transportation to medical facilities (Brouwer et al., 2000; Flaskerud & Tabora, 1998). These conditions might be observable in the current study as a high prevalence of the disease is found among the poorer communities.

Flaskerud and Tabora (1998) noted that carers also experienced loneliness, loss, anger, isolation and stigmatisation. Mental health problems in caregivers were associated with care receivers' memory and behaviour problems, anxiety and lack of knowledge about HIV/AIDS, while physical health problems were associated with depression, anger and the number of the care receivers' illness symptoms (Flaskerud & Tabora, 1998).

Leblanc, London and Aneshensel (1997) studied potential adverse impacts of caregiving on the physical health of informal HIV/AIDS caregivers, looking at both seropositive and seronegative participants with a mean age of 40 years. These researchers found that symptoms of poor physical health were markedly present among AIDS caregivers and were significantly associated with care related demands and stressors. It was noted that the seropositive caregivers experienced increased symptomatology independent of the actual demands and stressors of caregiving with increased role overload, while seronegative caregivers' poor physical health was increased by the PLWHA's depression, financial worry and assistance with various activities of daily living (ADL) i.e. bathing, dressing and feeding.

In a study carried out by Turner and Catania (1997) with caregivers aged between 18 and 49 it was noted that caregivers' burden raises with the characteristics of the caregiver and his/her relationship to the patient. Family members and gay friends were found to experience greater subjective strain in comparison to heterosexual friends. Lower income caregivers were more burdened in comparison to higher income caregivers as they had more caregiving demands (Turner & Catania, 1997). Men were also found to be more burdened.

Barbour (1994) studied the impact of caring for PLWA and found that the determinants of burnout in caregivers were related to the young age of the patients that were dying, neurological conditions presenting as a result of HIV/AIDS related illnesses, and that many caregivers have more intimate contact with patients thus presenting as a difficulty for caregiving.

Horsman and Sheeran (1995) found that distressing issues that were mostly reported by HIV/AIDS care workers were fear of infection, attitude towards sexuality, fear of social stigmatisation and concern about caregivers having the right to refuse providing care for PLWHA. Primary caregivers usually do not have a choice to refuse offering care to PLWHA, as circumstances (i.e. the relationship to the sufferer) force them to – unless the choice is made to abandon the infected person.

2.5.2 Social Support and Stigma

2.5.2.1 Social support and Caregiving

House et al. (1988, in Schwarzer et al., 1994) define social support as “the positive, potentially health-promoting or stress-buffering aspects of relationships” (p. 321). Other researchers define social support as “helpful functions performed by significant others such as family members, friends, co-workers and neighbours and thereby enhances the individual’s physical and psychological well-being” (Throits, 1986 in Petersen, 2000, p. 10). For the purpose of this study, social support will be understood as the helpful functions or supportive resources that are provided for primary caregivers of PLWHA to enhance their physical and psychological well-being. This social support is provided by significant others such as the family, partners, friends and neighbours, as well as formal caregivers in times of need.

Social support is categorised according to three types, namely emotional, cognitive and instrumental (Hansell et al., 1999). Emotional support consists of interactions behaviours that generate feelings of respect, comfort, and a sense of worth (Hansell et al., 1999). This is when others give reassurance to a caregiver. Cognitive support encompasses the giving of advice in order to equip an individual with knowledge and

information regarding the problems they are dealing with. Instrumental (or material) support refers to goods and services that are moved toward problem-solving.

Schwarzer et al. (1994) further distinguish between what they term perceived and received social support. Perceived social support is defined as “ a stable individual difference variable that is based on a sense of acceptance by others” and received social support as support that “deals with explicit behaviours by others intended to be helpful or perceived as helpful” (p. 321).

Owens (2003) studied African American women living with HIV/AIDS aged from 31 to 49 years to determine sources of support received from the family. It was noted that while all the participants experienced good emotional and concrete sources of support, the majority experienced little or no cognitive/informational support. Emotional support was experienced in a form of affective support (i.e. love, care, reassurances and sincere attempts encouragement), and family commitment, as well as acceptance, concern and empathy (Owens, 2003). Concrete or tangible support included accommodating the sufferer (offering a place to stay), assisting with parental responsibilities, activities of daily living, and providing transportation. According to Owens (2003), the lack of cognitive support was due to the families’ lack of awareness or denial of HIV/AIDS and its implications.

McCann and Wadsworth (1992), in their study on the utilization of statutory services, found that home visits were briefly carried out where there was a carer; where there was no informal carer the team would spend time talking to the person. Although home visits were carried out, informal carers felt that the care team supported the

PLWHA only, while 49% of the caregiver participants felt that they supported both the sufferer and carer (McCann & Wadsworth, 1992). There was insufficient emotional support as well as insufficient practical support for the caregivers.

Mullan (1998) reports that instrumental support when present plays an important role in minimising negative emotional experiences in caregivers. However, it is notable that carers dealing with HIV/AIDS patients lack this type of support as a result of other family members and neighbours being physically, emotionally or psychologically distant from the patient and caregiver (Mullan, 1998). Families as well as society avoid associating themselves with the infected and the affected as a way of protecting themselves from being stigmatised. This is due to lack of information regarding the manner in which an individual acquires the disease.

2.5.2.2 Stigma and Caregiving

Research on stigma dates back to Goffman (Poindexter, 2005 and Poindexter & Linsk, 1999). He was the first social scientist to conduct extensive research on this issue. Goffman (1963 in Poindexter, 2005) viewed stigma as powerful discrediting and tainting social labels that radically change the way individuals view themselves (having undesired “differentness” or spoilt identity) and are viewed by others (seeming immoral, a disgrace or irresponsible).

Three concepts related to stigma identified by Goffman in his studies are associative stigma, internalised stigma and stigma management (Poindexter & Linsk, 1999). Associative stigma, also known as “courtesy stigma”, is stigma experienced by individuals who are voluntarily attached as caregivers or are acquaintances to people

who are stigmatised (Poindexter, 2005). This results in individuals being isolated, hidden, fearful and stressed. Caregivers become uncertain about how people will identify, receive and treat them, and as a result become secretive and defensive.

Internalized stigma is when an individual or groups accept that they deserve to be treated poorly and unequally, making resistance to stigma and resulting discrimination even more difficult (Poindexter & Linsk, 1999). Stigma management refers to “purposeful strategies used by a stigmatised person or associate to lessen ostracism and blame by concealing the condition” (Poindexter, 2005, p64-5). In a study carried out by Poindexter (2005), it was noted that the caregiver actively dealt with associative stigma by challenging the negative behaviours and discriminative remarks uttered by family members and other societal members directly and indirectly to PLWHA -- by correcting and confronting those that stigmatised the infected people.

Katz (1981) argues that stigma encompasses a perception of negative characteristics and a global devaluation of the possessor of the characteristic. Issues of isolation and rejection, and subsequent prejudice and discrimination, stem from the fact that people often try to avoid interaction with individuals whose bodily and psychological characteristics deviate from the norms of family members and society. Those who are different (the PLWHA and their caregivers) wish to avoid situations where their differences may be problematic for themselves and others.

The stigma in most cases leads to isolation from usual support networks. This results in fear to disclose the illness to other family members, friends and neighbours. It is common for the affected as well as the infected to rather speak about opportunistic illnesses, explanations or attributions, like meningitis or pneumonia, to avoid rejection

and humiliation because of the stigma associated with this illness (True Love, May 2002; Powell-Cope & Brown, 1992). According to Powell-Cope and Brown (1992), the caregiver and the sufferer are vulnerable to the effects of stigma such as “isolation, emotional turmoil and shame” (p. 578). This could possibly lead to poor coping strategies as a result of poor social support because carers are resistant to disclosing what they are really dealing with. It is found that carers tend to keep this a secret and deal with it alone (True Love, May 2002; Powell-Cope & Brown, 1992).

2.5.3 Coping

2.5.3.1 Definition of Coping

Coping is defined as “the cognitive and behavioural efforts made to master, tolerate or reduce external and internal demands and conflicts among them” (Lazarus & Folkman, 1980). Lazarus and Folkman (cited in Rose & Clark-Alexander, 1999) define coping as “a person’s constantly changing cognitive and behavioural efforts (used) to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person”, (p. 337). Lazarus and Folkman (1980) classify coping responses as either problem-focused or emotion-focused. Problem-focused coping, known as confrontive coping, is that strategy used by the individual to identify causative factors for an occurrence, and then devising means and ways of dealing with that in an effective manner (Rose & Clark-Alexander, 1999).

This form of coping is goal-directed as it is directed at defining the problem, generating alternative solutions, weighing costs and benefits, and then choosing and acting on a solution. Examples of confrontive coping include bargaining, focusing on the positive, social support, and concentration of efforts (Sarafin in Melnick, 2004).

Emotion-focused coping, also known as passive and emotive coping, is the avoidance of a problem which can be used to maintain hope and optimism; but it can also be used to deny both the facts and implications of the facts, and to act as if what has happened does not matter - that is, the impact and consequences do not have to be addressed (Rose & Clark-Alexander, 1999). It is generally used when individuals believe they are unable to change a stressful situation. Emotion-focused responses include cognitive escape-avoidance, behavioural escape-avoidance and distancing as a result of poor outcomes, such as high levels of depression (Folkman et al., 1994).

Apart from the coping responses discussed previously, researchers have identified many other types of specific coping strategies. Carver, Scheier and Weintraub (1989) criticised the Ways of Coping Scale constructed by Lazarus and Folkman (1980) as not having all the specific domains of theoretical interest and as lacking focus in some items. Based on theoretical arguments about functional and potential properties of coping strategies, an instrument incorporating thirteen (13) conceptually distinct scales was developed. This is called the Multidimensional Coping Inventory (Carver, Scheier & Weintraub, 1989). Scales covered include active coping, planning, suppression of competing activities, restraint coping, seeking social support for instrumental reasons, seeking social support for emotional reasons, focusing on and venting of emotions, behavioural disengagement, mental disengagement, positive reinterpretation and growth, denial, acceptance and turning to religion (Carver, Scheier & Weintraub, 1989).

According to Folkman (1997), coping theory has focused on coping processes that help to manage or reduce aversive states. She therefore proposed a model that

considers the two sets of issues; namely, the kinds of coping processes that support positive psychological states in the midst of highly stressful circumstances and the significance of positive psychological states in the coping process.

2.5.3.2 Previous Research on Caregiving and Coping

Research linking caregiving and stress has been taking place for many years. Several reasons explain this striking growth of interest. According to Perlin et al. (1990), one of these reasons concerns the changing demographic landscape of contemporary societies: People live longer, and therefore are more at risk of chronic ailments that impair their ability to care for themselves. As a result of medical advances, they survive for longer periods of time despite their health problems, consequently needing those that can care for them.

Today, people are infected with HIV/AIDS, which leads to debilitation as the disease progresses - irrespective of age at infection - thus needing someone to care for them. Stressors are experiences, conditions and activities that are problematic to people, threatening them, and thwarting their efforts, resulting in their dreams ultimately being defeated by fatigue. Coping and social support are the two principal mediators used by researchers to measure whether people exposed to seemingly similar stressors are affected by them in dissimilar ways.

Dorz et al. (2003) assessed burnout and coping strategies among HIV/AIDS and oncology care workers (i.e. doctors & nurses) looking at levels of emotional exhaustion (EE), depersonalisation (D) and personal accomplishment (PA) using the Maslach Burnout Inventory (MBI), The Coping Orientation to Problem Experiences (COPE), State-Trait Anxiety Inventory (STAI) and Depression Questionnaire (DQ).

The result from this study revealed a low degree of burnout among health workers as indicated by low scores of EE and D and moderate scores on PA. The findings further showed a greater frequency of D among the doctors in comparison to the nurses. The researchers found this to be strange, as nurses spend more time than doctors do with patients.

This was interpreted that possibly the greater amount of time having contact with ill people might serve as a protector against burnout. Planning (i.e. to reflect and to develop a strategy to get over a problem) and restraint coping (i.e. to avoid acting impulsively, waiting for the right moment to cope with stress) were predictive factors for PA. Using denial and humor were associated with EE and D, with humour reflected as an inadequate coping strategy because of its use of ridiculing, laughing, and trifling about the situation (Dorz et al., 2003).

The context in which a stressful event occurs, as well as the demographic variables of age and gender, influences the kinds of coping used by individuals to cope with stress. Research indicates that individuals, when faced with a stressful situation, are more inclined to use problem-focused coping than emotion-focused coping, as it is seen to be more effective.

In a study conducted by Rose and Clark-Alexander (1999), assessing coping styles and the quality of life of non-parental caregivers of children with HIV/AIDS, confrontive coping was most often used, with passive and emotive coping used less often. The number of children cared for was significantly positively related to confrontive coping, and significantly inversely related to passive and emotive styles

of coping. Alcohol usage and feeling depressed were found to be significantly positively related to emotive and passive coping.

Lazarus and Folkman (1989) found that the choice of coping strategies used appeared to be influenced by factors such as self-esteem, whether stress experienced involved family members, and the degree of control an individual felt they had over the stressful situation. Self-control, confrontive coping, accepting responsibility, escape avoidance and a reduction in seeking social support are used when a person feels that their self esteem is threatened (Lazarus & Folkman, 1989). In a related study conducted by Driedger and Cox (1991 in Melnick, 2002) it was noted that inexperience was significantly related to the level of emotional exhaustion reported by the nurses. This has possible implications in South Africa where caregivers are increasingly younger and the siblings to the sufferers.

Folkman (1997) examined the effect of caregiving and bereavement on the mental and physical health of partners of men with AIDS. Four types of coping processes were identified which were associated with positive psychological states during caregiving and bereavement: Positive reappraisal, goal-directed problem- focused coping, spiritual beliefs and practices, and the infusion of ordinary events with positive meaning. These types of coping have a common theme, which is searching for and finding positive meaning as they involve the activation of beliefs, values, or goals that help define the positive significance of events (Folkman, 1997). Meaning is created by finding redeeming values in a loss, such as being advocates for research on that disease, formulating new closer bonds with others because of having experienced or survived a natural disaster together, and by pursuit and attainment of important goals

(Folkman, 1997). Caregiver studies have also revealed that positive effects are related to the use of positive reappraisal, deriving satisfaction from caregiving, and problem-focused coping.

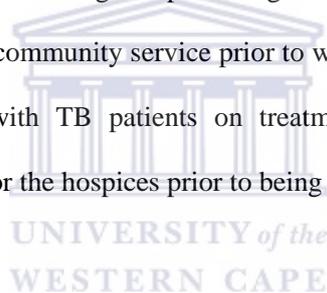
In a study executed by Catalan et al. (1996), the General Health Questionnaire (GHQ) subscores indicated the presence of social dysfunction and somatic and anxiety symptoms in health workers, with nurses reporting high levels of somatic symptoms. Catalan et al. (1996) found informal support and religion were used as coping mechanisms by AIDS and oncology nurses and doctors. Situations that were found difficult were caring for people with deteriorating health, those in terminal stages, young patients, and dealing with their psychological problems as well as those of their families (Catalan et al., 1996).

2.5.4 South African Research and HIV/AIDS Caregiving

Melnick (2002) conducted a study on home-based caregivers to determine their coping strategies using the Ways of Coping Questionnaire. The results revealed that feelings of pain, difficulty performing the work due to discrimination and stigmatisation by society, poverty and inaccessibility of hospital and professional medical supports were the major concerns. Feelings of helplessness were expressed, especially with dying patients. Coping mechanisms employed were faith, trying to control feelings, and asking for support from colleagues and families (Melnick, 2002). The caregivers expressed a need for training, support groups, financial support, food supply and safety for sufferers.

In a study carried out by Van Wyk (2002) on home-based carers of PLWHA to determine the level of burnout and to compare the findings to those of other caregivers involved in other kinds of patients care, there was no difference observed between the two groups. Gender and language were significant predictors of emotional exhaustion (EE). With regard to language groups, regarding EE there was a significant difference among the three groups: EE was observed to be high among Xhosa-speaking carers compared to the others. This might either be related to the fact that English is their second language, or that the instrument was constructed in America.

Uys (2002) conducted a study at seven sites in South Africa to describe the practices of community caregivers in a home-based care project. Participants in the study were aged from 20 to 49 with most of them having completed high school education. Most of the caregivers had experience in community service prior to working for the home-based project, such as working with TB patients on treatment, trained as lay-counsellors, and have volunteered for the hospices prior to being employed.



Caregivers reported economic constraints of the care recipients as a challenge to their jobs, as PLWA were unable to buy food to eat in order to take treatment effectively. Other concerns included the inability to deal with psychiatric conditions and symptoms. However, although the carers had these challenges, they were observed to be working in close collaboration with the South African Hospice Association and other community organisations within their areas, as well as with area clinic staffs. This served as a buffer to the stresses they experienced.

Although the three aforementioned studies are South African based and the two were conducted in the Western Cape, these studies look at voluntary caregivers who have a certain level of training. Secondly, these participants are within organizations that might at the time of research be looking at support structures for their workers to decrease stress levels, e.g. the caregivers support group run for caregivers within St. Luke's Hospice (St. Luke's website).

Thirdly, carers from these organizations do have a working distance as they have a limit to the number of hours they are in contact with their clients. Lastly, although Uys (2002) employed qualitative research methods, the researchers were eliciting the practices of caregivers, and therefore did not look at their coping styles for the challenges they were experiencing. Melnick (2002) and Van Wyk (2002) used quantitative research with qualitative analysis applied to open-ended questions on a standardised questionnaire, and therefore did not capture the essence of caring as might be experienced by the carers. It is on these grounds that a qualitative research study of informal PCG who do not have any form of training in caregiving, and who have limited support structures, needed to be conducted. These PCG needed to be given an opportunity to voice out their experiences and their coping styles, as well as to ascertain the support structures available to them.

2.5 Summary

The chapter has outlined the stages of the disease to give an idea as to the physical changes occurring for PLWHA, which determine the demands on caregivers. A salient literature review reveals the experiences of primary caregivers as observed by other researchers. Social support is noted as a buffer for strenuous experiences, but

with HIV/AIDS primary caregivers it is noted that it is difficult to obtain social support as a result of stigmatisation. Poverty is also observed to be aggravating the physical as well as the mental well-being of PCG. With regard to coping, confrontive coping has been observed as the type of coping mechanism that is used by individuals who find them in a strenuous situation. The chapter ends by looking at the scarcity of research on HIV/AIDS PCG within the South African context.



CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

3.1 Introduction

This chapter begins by stating the aims of the research, as well as the questions it intends looking at, as stated in Chapter One. The chapter further details the methodology employed in the present study. It continues with the research design, and then describes the participants and the sampling technique. This is followed by a description of the data collection and data analysis. The chapter ends with the ethical considerations that arose in the conduct of this study.

3.2 The Aims of the Study

The aims of the study are:

- ◆ To explore the psychosocial experiences of HIV/AIDS primary caregivers.
- ◆ To understand the coping strategies employed by these caregivers to deal with their feelings, as well as the responses of the public towards them.

Three main questions that this study answers are:

1. What are the experiences of caregivers living with and taking care of someone with HIV/AIDS?
2. How have others responded towards the caregivers knowing that they are caring for someone with HIV/AIDS?
3. How do caregivers deal with their experiences, particularly their feelings and as the manner in which society responds to them?

3.3 Research Design

This study is located in a qualitative research paradigm. Qualitative designs are naturalistic, allowing the researcher to engage in a naturalistic enquiry. This makes it possible to gain both depth and detailed information concerning the phenomenon of interest without manipulating the research setting (Strauss & Corbin, 1990). According to Ulin et al. (2002), the purpose of qualitative research is to “generate knowledge of social events and processes by understanding what they mean to people, exploring and documenting how people interact with each other and how they interpret and interact with the world around them” (p. 26). Other aims of qualitative research are to elicit meaning and gain novel and fresh slants on things that little are known about, as well as giving intricate details of phenomena that are difficult to convey with quantitative methods (Strauss & Corbin, 1990).

This paradigm uses holistic methods of gathering and examining information. Furthermore, it involves direct personal contact with the participants of the study and uses inductive logic (i.e. making specific observations and building toward general patterns) in order to analyse data that has been gathered (Strauss & Corbin, 1990). All these factors combined with the interpretive focus of qualitative research make it an ideal paradigm for investigating the experiences of HIV/AIDS PCG.

3.4 Participants

Qualitative research makes use of a small number of cases to study a phenomenon in depth (Patton, 1997). By using small sample sizes, the researcher is committed to discovery through the use of multiple ways of understanding. It is possible for the researcher to use more than one method (e.g. interviews and observations), (Speziale

& Carpenter, 2003). The current study aims to understand the experiences and coping strategies of PCG of PLWHA from participants' viewpoints. Because people do understand and live experiences differently, qualitative researchers do not subscribe to one truth, but rather to many truths. Eight primary caregivers participated in the study. The participants were chosen from Khayelitsha and Gugulethu with four participants from each site. All participants were Africans, young adults aged between 20 and 44. Each participant was providing care to young adults within the same age category who had progressed to stages III and/or IV of HIV/AIDS (i.e. – meaning the care recipients had distinctive signs and symptoms as described by the World Health Organization (WHO)).

All the participants had not had any form of formal training in caring (i.e. had not undergone any course related to home-based care). Participants consisted of both men and women; their care recipients were also men and women. The reason for having both male and female caregivers is that though in the past caregiving was associated with women, ever since the recognition of HIV/AIDS it was found that men do also become caregivers. It was also noted that, in the past, women were perceived to be more emotional in comparison to men, and consequently were perceived to be unable to cope with certain challenges. Since the study sought to look at experiences and coping strategies of primary caregivers in general, it was therefore of great value to understand it from both a male and a female perspective. Participants were recruited through a Non-Profit Organisation that uses volunteers to assist PCG at home.

3.4.1 Demographic Data of the Participants

Of the eight participants interviewed in the study, three (37.5%) were males while five (62.5%) were females. The majority of the participants (62.5%) were in the age group 40-44, while two (25%) were aged between 30 and 39, and only one (12.5%) was aged between 20 and 29 years of age. The mean age of the participants was 39.63.

Three (37.5%) of the participants were not married, two (25%) were married, and two (25%) have lost their spouses through death, while one (12.5%) had separated with the spouse recently due to marital problems associated with the commitment of caring for family sick members. Regarding the educational level of participants, it was found that one (12.5%) had no schooling, three (37.5%) had passed Standard 6, one (12.5%) had passed Standard 7, one (12.5%) had passed Standard 8, one (12.5%) had passed Standard 9, and only one (12.5%) had a Senior Certificate.

Most of the participants (62.5%) were unemployed; two (25%) were on casual jobs, while one (12.5%) had permanent employment. Of the eight participants, two (25%) were breadwinners, whereas five (62.5%) depended on social grants, and one (12.5%) was assisted by distant family members to support the family. (Refer to table 1 for details).

Five (62.5%) of the caregivers gave care to one care recipient, two (25%) gave care to two care recipients, while one (12.5%) cared for four care recipients. Three (37.5%) cared for their siblings, one (12.5%) cared for their spouse, one (12.5%) for their children, one (12.5%) cared for a parent and the sibling, one (12.5%) cared for a

sibling and niece, while one (12.5%) cared for their in-laws. Unlike with the study of McCann and Wadsworth (1992), which found that caregivers were mostly friends and partners of PLWHA, in the present study the majority were siblings and others.

Table 1: Demographic data of participants

Characteristic variable	Participants (n = 8)
Sex: Male	3 (37.5%)
Female	5 (62.5%)
Age: 20-29	1 (12.5%)
30-39	2 (25%)
40-44	5 (62.5%)
Marital status: Married	2 (25%)
Not married	3 (37.5%)
Lost spouse through death	2 (25%)
Separated	1 (12.5%)
Educational level: No schooling	1 (12.5%)
Standard 6	3 (37.5%)
Standard 7	1 (12.5%)
Standard 8	1 (12.5%)
Standard 9	1 (12.5%)
Standard 10	1 (12.5%)
Occupational status: Employed-full time	1 (12.5%)
-Casuals	2 (25%)
Unemployed	5 (62.5%)
Number of care recipients: 1	5 (62.5%)
2	2 (25%)
4	1 (12.5%)
Relationship of sufferer to carer: Siblings	3 (37.5%)
Spouse	1 (12.5%)
Children	1 (12.5%)
Parent/sibling	1 (12.5%)
Sibling/Niece	1 (12.5%)
In-laws	1 (12.5%)

3.4.2 Demographic Data of the Care Recipients

Of the 13 care recipients, 11 (84.6%) were diagnosed with HIV only, one (7.7%) suffered from cancer and one (7.7%) had both HIV and cancer. 12 (92.3%) of the care recipients were females, while only one (7.7%) was a male. Only nine (69.2%) of the care recipients met the research criteria (meaning they were aged between 20 and 44).

Although questions were directed in such a way that the information obtained could be related to those meeting the requirements, there were instances when the information was generalized. Age distribution was as follows: One (7.7%) of the care recipients was <20, seven (53.8%) were aged between 20 and 29, four (30.8%) were aged between 30 and 39, and only one (7.7%) was aged above 44. Of the 13 care recipients, only three (23%) of them were employed prior to being sick and had lost work due to illness, while seven (54%) were unemployed and three (23%) were still schooling.

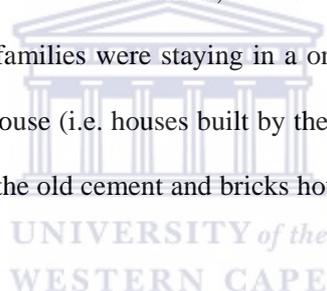
Of the 13 recipients, nine (69%) had children and four (31%) had no children. Of the nine (69%) who had children, six (46%) had less than three children and three (23%) had more than three children (Refer to Table 2 for details regarding characteristics of care recipients). Of the 13 care recipients, six (46%) were on anti-retroviral therapy (ARV), with only two (15.3%) of them on the treatment for more than a year.

Table 2: Demographic Data of Care Recipients

Characteristics of care recipients	Number of care recipients (n = 13)
1. Gender: Male	1 (7.7%)
Female	12 (92.3%)
2. Age distribution: <20	1 (7.7%)
20-29	7 (53.8%)
30-39	4 (30.8%)
40-44	0 (0%)
>44	1 (7.7%)
3. Employment status prior to illness: Unemployed	7 (54%)
Employed	3 (23%)
Schooling	3 (23%)
4. Number of children: No children	4 (31%)
Less than 3 children	6 (46%)
More than 3 children	3 (23%)
5. Anti-retroviral therapy	6 (46%)

3.4.3 The Living Background of the Participants

Regarding the number of people within the household, it was found that the number differed from 5 to 11. Most of the families were staying in a one-bed roomed house that was either a shack or an RDP house (i.e. houses built by the government housing project), with only a few staying in the old cement and bricks houses of about three to four rooms.

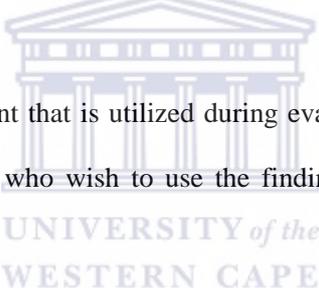


With regard to the period the caregivers had spent caring for the care recipients, the response differed from a minimum of a year to a maximum of ten years. Most of them did not really know for exactly how long it had been, although they could say it had been for a lengthy period. Regarding the caregivers' knowledge of what was wrong with the sufferer, most of the caregivers first knew the sufferer as having tuberculosis (TB), cancer or meningitis; other co-morbid diseases included sugar diabetes and stroke. Knowledge of the HIV diagnosis happened after they had been providing care

for some time. Only one carer knew the diagnosis before the onset of the illness as the care recipient was diagnosed during the antenatal period (i.e. during her pregnancy).

3.5 Data Collection

In qualitative research the researcher is the instrument of data collection and the credibility of the data collected is dependent on the skill of the researcher (Strauss & Corbin, 1990). Different data collection methods can be employed depending on the field of interest, as well as how much information is required. Four types of data collection procedures in qualitative research are: Observations, interviews, documents and visual images (De Vos et al., 1998). In this study, in-depth interviews were used as the primary form of data collection. A semi-structured, open-ended interview schedule was developed. This method of gathering information from the respondents was employed for the following reasons cited by Patton (2002):

- 
- ◆ The exact instrument that is utilized during evaluation can be made available for those who wish to use the findings of the study and replicate the study.
 - ◆ Because the interview is focused, the time is used efficiently.
 - ◆ When analysing the data, it makes it easier to find and compare responses.

According to Kvale (1996), qualitative interviews are theme-orientated, and are neither strictly structured nor entirely non-directive. The interviewer flexibly followed a pre-prepared interview guide. The guide was first piloted on three participants from

different age groups of the caregivers before being utilised for validation. The use of an interview guide ensured the interview process was standardised across participants.

In-depth interviews involve one-on-one, face-to-face interaction between an interviewer and an interviewee. They seek to build the kind of intimacy that is necessary for mutual disclosure (Johnson, 2002). The study is located in a phenomenological theory, thus seeking to understand the phenomenon of living and caring for PLWHA. In-depth interviews were utilized to seek deep information and knowledge regarding the experiences and coping strategies of HIV/AIDS PCG (meaning of participants' actions will be learned). The aim was to explore the contextual boundaries of that experience, to reveal what is usually unknown to the ordinary observer. This allows a more reflective understanding about the nature of those experiences.

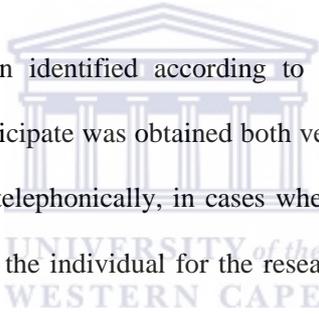
3.6 Research Procedure

Permission to access participants through home-based community caregivers was requested from the Education Department of St Luke's Hospice in Kenilworth. After permission was granted, contact details for two community caregiver supervisors based in the Gugulethu and Khayelitsha area were obtained. Preliminary meetings were set between the researcher, the community caregivers' supervisors and home-based caregivers in Gugulethu and Khayelitsha for February 2004.

The researcher explained the research purpose and the kind of participants required to take part in the research. The aim of these meetings was to identify possible candidates, and for the home-based caregivers to accompany the researcher to the

participants' homes, as she was not familiar with the area and PCG would not be able to come to the day care centres. A convenient sample was chosen. Willingness to participate was also of great importance to the researcher.

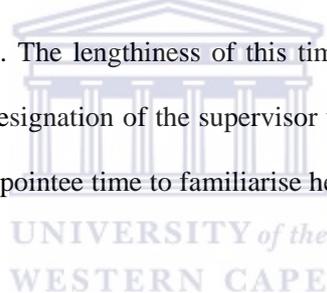
At first, three participants were randomly selected, without limitations put on the age of the PCG or that of the sufferers, in order to pilot the interview guide designed by the researcher. This took place in March 2004. After piloting, the researcher re-worked the guide and re-checked it with the supervisor before going back into the field. The revised version of the interview guide consisted of a set of questions relevant to the three main questions the research aims to answer. It also consisted of the demographic data in order to understand the social circumstances of the participants as well as those of their care recipients.



The suitable participants were then identified according to the requirements, as previously stated. Permission to participate was obtained both verbally, for those who could be physically identified, and telephonically, in cases whereby the home-based carers would not be able to prepare the individual for the researcher or whereby the PCG was working. Prior to interviewing participants, the researcher obtained written consent from the participants for participation as well as permission to audiotape interviews. It was explained that the taping was for data analysis purposes, so that the researcher could pick up anything that might have been missed during the interview process. The researcher also explained that the audiotapes would remain the property of the researcher and would be destroyed after completion of analysis.

Seven (87,5%) of the interviews were conducted in the comfort and convenience of the participants' home at times suitable to them, while one (12.5%) was conducted at the St. Luke's Hospice In-patient Unit as the participant was eager to talk to the researcher as a way of taking off the load that the participant was feeling inside. Interviews were done in the language convenient to participants, which was mostly in Xhosa. The interview guide was first prepared in English and then translated into Xhosa, in order to accommodate participants who were not able to express themselves in English.

Interviews lasted on average one hour, with the longest interview being one hour and 45 minutes and the shortest being approximately 30 minutes. For participants who became emotional during the interview process, the researcher did spend some time comforting and empathising with them. The interviews were conducted from November 2004 to December 2005. The lengthiness of this time period was due to personal reasons, as well as to the resignation of the supervisor within the Gugulethu area; the researcher gave the new appointee time to familiarise herself with her clients before recommencing.



3.7 Data Analysis

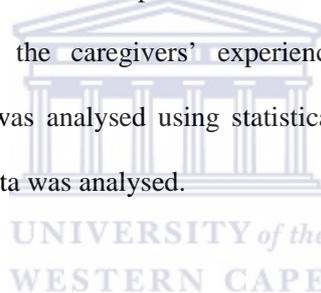
Data analysis involves breaking up the data into manageable themes, patterns and trends. The aim of analysis is to determine whether any pattern or trends can be identified or isolated, or to establish themes in the data (Mouton, 2001). As a first step of the data analysis process all audio-recordings were transcribed. This ensured that the richness of the text was not lost. Transcripts were then translated from Xhosa into English by someone who is fluent in both languages working for Illwimi Sentrum at

the University of the Western Cape. Verbatim transcripts were then analysed by means of thematic content analysis.

Thematic content analysis is a process of breaking down the text into themes and categorising the patterns in the data (Terre Blanche & Durrheim, 2002). The steps for the method followed are those outlined by Terre Blanche and Durrheim (2002, p. 140):

- ◆ Familiarising and immersing in the data,
- ◆ Inferring themes that arise naturally from the data but also relating to the research question,
- ◆ Coding (breaking up the data into analytically relevant ways),
- ◆ Exploring themes in greater detail and
- ◆ Checking, before the final interpretation.

All themes emerging concerning the caregivers' experiences were considered important. The demographic data was analysed using statistical analysis where the frequency, mean and mode of the data was analysed.



3.8 Ethical Consideration

Permission to conduct research was obtained from the participants, as well as from the Education Department of St. Luke's Hospice in Kenilworth, in order to access their patients in Gugulethu and Khayelitsha. Informed consent to participate, to record the interviews, and to use the information was obtained from participants prior to conducting the interviews. Anonymity and confidentiality of all participants was ensured. Participants did participate voluntarily, and participants were informed that they could withdraw from the study at any time should they so wish. To ensure that

the information was relevant and a true reflection of the information obtained from participants, verbatim transcripts were represented to participants for scrutiny prior to analysis. The research findings will be presented to St. Luke's Hospice, and a copy will be made available to their Education Department on completion.

3.9 Summary

The chapter begins by looking at the aims of the study, as well as the main questions that the study is looking at. The study is then located within a research paradigm and the reason for choosing a qualitative paradigm is discussed. The participants of the study are discussed, together with the data collection method used for the study. The researcher then looks at the procedures she undertook to recruit participants and to conduct the interviews with these individuals. The chapter ends by looking at the data analysis method and the ethical considerations.



CHAPTER FOUR

RESULTS AND DISCUSSION

4.1 Introduction

This chapter looks at the findings of the research based on the thematic content analysis of the verbatim transcripts of the eight interviews. Several prominent recurring themes and sub-themes emerged across the eight interviews. The three dominant themes to emerge were:

1. The Caring Experience
2. Family and Community Responses
3. Managing the Role of Caring and the Societal Response

These three dominant themes depict the experiences and the coping styles used by primary caregivers of HIV/AIDS sufferers who have progressed to stage III and IV of the disease. The themes will be continually compared to previous research, in order to elicit how they give depth and insight into the previous findings on the experiences and coping strategies of HIV/AIDS primary caregivers.

4.2.1 Theme 1: The Caring Experience

Three questions based on this category theme were asked to the caregivers. Among the three questions there were commonalities that occurred, primarily revealing the emotional ambivalence, the economic constraints, and the physical challenges experienced throughout the caring process. Each theme will be discussed with its supporting sub-themes, as expressed by caregivers. Verbatim quotes will be attached to give meaning and understanding to the theme.

4.2.1.1 Emotional Ambivalence

Ambivalence refers to the coexistence of opposing feelings. What emerged is that the caring experience is an intensely emotional process. Within that, respondents reported different aspects of this emotional process, which were called upon in being a carer.

These emerged as follows:

a) Emotional Roller-coaster

A lot of emotional issues surfaced from the participants, which were uncontrollable and unstable. One of the carers, due to his knowledge about the disease, described anticipating a positive diagnosis while he was caring for the sufferer. This is what Mr.

A said:

“ ...I’ve long been seeing her, I used to attend support groups at...I became aware of symbols (signs and symptoms), I became observant of her and noticed these, so I told myself that ... get ready emotionally and I advised her to take a step to follow up (get herself tested) and she also did take my advice then she found out that really she is positive (Have acquired HIV)”.

Although he anticipated the diagnosis, he expressed a lot of conflicting feelings when his suspicion was confirmed. Just like Mr. A, carers expressed their wide range of feelings when they first heard about their loved ones’ HIV diagnosis. Carers expressed being shocked, feeling sad and hurt, as well as being disturbed by the HIV diagnosis. These were the expressions of the carers:

Mr. B said: *“...I took her to the clinic one morning for follow-up, the counsellor did not want me to go in with her telling me that my sister’s illness*

is her own business...then my sister said to her 'I would like my brother to know what is wrong with me as he is taking care of me' she said she is prepared to tell me about her illness...that she is positive. I was so shocked".

On the other hand Ms C said that, *"I was shocked and disturbed, remember she is my biological sister and the youngest"*.

Ms F said: *"I was very hurt about (Name) because she is in school and this disturbed me. Even if she was doing her things they were not shocking because she went to school very well"*.

Ms G said: *"I feel so sad, don't know what to do or say. I feel so sad when they are very sick, but when they are better I feel well too"*.

Discussion

This theme is supported by Keene Reder (2003) who reports that caregivers and PLWHA experience what is termed anticipatory grief, which is associated with the development of symptoms that people perceive as life-threatening. It is noted that with his knowledge of the disease progression, even without knowing the true diagnosis, the carer (Mr. A) prepared himself emotionally to adapt to role changes. Advising the sufferer to go for an HIV test reaffirms changing assumptions, and creates an opportunity to face the reality of the matter.

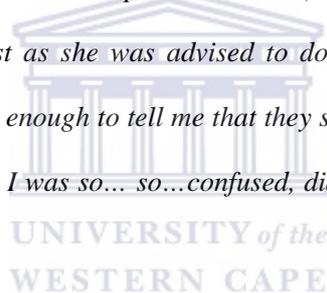
Pakenham, Dadds and Terry (1995) noted that caring increases distressing emotions. Within this study it was also noted that caregivers experienced a lot of emotions ranging from shock, hurt, sadness, and feeling very terrible - as expressed by Mr. A. Caregivers did not only utter these words, but it could also be observed from their body posture and the way they expressed themselves. Some of them were very tearful

when remembering that moment. As similarly stated by Edelman (2000), it was also observed in the present study that emotional experiences were aggravated by the relationship of the caregiver to the care recipient, as noted in Ms C's comment that she was her biological sister.

b) Emotional Confusion

Although the other participants expressed feeling grateful to the sufferer for being able to disclose the diagnosis, a feeling of confusion followed. Living with and being intimate with the sufferer brings up questions of "What if...?" for the carer. This becomes a very difficult situation, as the carer is divided between having to care and having to establish what it all means as an individual and as an intimate partner. This is how Mr. H put it:

"My wife went to see a Dr. for check-up as she was (hand-signal: denoting pregnant). She then went to test as she was advised to do that. I was grateful about that ... that she was brave enough to tell me that they said at the clinic after testing her, she is positive. Then I was so... so...confused, did not know whether I had it or not".



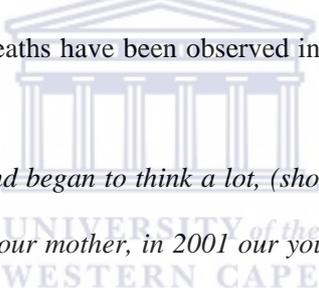
Discussion

The issue of emotional confusion is less highlighted. Edelman (2000) found that caregivers experience feelings of low morale, stress, fatigue and anxiety, as well as hopelessness about the future. In this context, confusion can lead to anxiety and hopelessness about the future, as it isn't known what it is he/she is faced with. It can also lead to poor self-esteem, which might result in secrecy and isolation. Edelman (2000) also states that the relationship of the carer and the recipient aggravates the

emotional experience of the caregiver. This was the case for Mr. H, where confusion was created and intensified by the fact that this was someone that he was intimate with, who also was pregnant with his child, aggravating his emotional distress at the possibility of him also being positive. This can later bring difficulty in caring, as the caregiver is intimately related to the care recipient.

c) Fear of Death

Hearing of someone's HIV diagnosis also raises a lot of questions in one's mind, especially when one is family and depends on that individual for support. Being attached to each other and being supportive of each other as siblings enables one to deeply explore what a positive HIV result could mean. Most people regard an HIV diagnosis as a death sentence, and thus being diagnosed with the disease means losing the loved one to death. Carers expressed having a fear of death for their loved ones, and this was even severe when multiple deaths have been observed in the family, as stated by Mr. B:



"I was so scared and began to think a lot, (shoo) in 1989 we buried our father, in 2000 our mother, in 2001 our youngest sister so I was scared that she is next since as you also know that HIV/AIDS (shook his head) is a disease that kills".

Ms. D said: *"She is not worrying a lot about it but I sometimes worry about what if...if something could happen to her. I don't want her to die now. I would like her to see how her youngest one grows".*

Discussion

According to Mullan (1998), caregivers experience a lot of difficulties that have to do with patient comfort, especially when patients are acutely ill or cognitively impaired. The fear of death of those they care for is a constant threat. It has been noted that fear of death in this study was also a constant threat to caregivers. Several caregivers expressed their fears of losing their loved ones as a result of being positive. This is due to the fact that the positive result (or being known as HIV+) automatically is associated with death. Although there are ARV's and positive lifestyle habits that can prolong an individual's life, it was noted that poor lifestyle, lack of knowledge and poverty increased fear of death on the caregivers and sufferers. In other instances, it (death) became a threat when an individual had experienced multiple losses; therefore being faced with an HIV positive family member brought up issues around future implications for the caregiver, the family at large, and to the sufferer him/herself.

d) Suffering Multiple Losses

Fearing the death of a loved one causes an individual to become worried about what that will really mean to him/her. Although most of the participants were worried about the sufferer's well-being, some of the caregivers' main worry was around the sufferers' children. Having a child within the African culture carries a great meaning, like being an heir within the family or having to keep the family name in existence. Others were worried that the sufferer was childless, as the child would have served as a reminder should the person pass on. This led to suffering a string of losses: the loss of having the recipients' children as a remembrance, and the loss of bringing up their children, caring for and nurturing them. Other carers indicated crying, which denotes grief among the caregivers. These were noted from these carers: Mrs C said:

“What worries me most is that he does not even have children. This could have been better if he had children of his own that were going to remind us of him. Should he die there will be nothing at all”.

Ms. D on the other hand said:

“What worries me most is her child, this young one” while Ms. G said:
“When she is worse I become very worried. My sister have four children and I have three, my main worry is these children should anything happen, I really do not know”.

Loss did not only include worrying about having children or caring for the children of the sufferer. For others it included a *loss of intimacy*, as one of the caregivers said:

“My wife is no longer interested in sex.... But I am fine with it. I respect her decision and I do support her feelings, I cannot do anything....”

Other caregivers experienced the *loss of support* accompanied by the *loss of income*. One of the caregivers stated that only the two of them were remaining; the sufferer was taking care of the household chores, and he (the caregiver) depended on her for everything. Not only this, but the sufferer also lost her job, as her employers were afraid she might infect them with TB. They advised her rather to stay at home, and to bring someone to stand in for her until she is fully recovered. This family is currently depending on the money that the carer makes through ‘char-work’, referring to piece jobs. Mr. B said

“... she developed TB and her employer asked her to bring someone to hold for her until she feels fine as she will infect them. She never went to work

again as she became worse...She also knows that I do not have a wife...I depended on her for cooking, cleaning as well as washing.”

Discussion

Experiencing a sense of loss prior to the actual death of the care recipient has been supported by Mullan (1998), who sees this as a primary source of the stress of caregiving. Mullan (1998) states that caregivers respond to primary stressors with subjective stressors, such as “feelings of loss, overload and being a captive to caregiving demands”. Suffering losses can be overwhelming for both the caregiver and the care recipient. Anticipatory grief takes its toll as the caregivers are making assumptions about what the future holds for them, e.g. more challenges, dealing with the financial burden, demands of bringing up children and the pain of bereavement. Flaskerud and Tabora (1998) also found in their study that carers experience loss.

4.2.1.2. The Economic Challenge

Most of the caregivers were not working, with the majority depending on pension funds/social grants, causing an adverse financial impact. Caring for a terminally ill individual can be financially demanding, due to medical costs and a need to feed the ill-person healthy food. Some of the caregivers were burdened by financial constraints, leading to stress and frustration. These were views expressed by different caregivers:

Mr A stated that: “...Yesterday she was so terrible, I called for the ambulance at 16h45 and only arrived at 10pm. If we had money I could have hired someone. And today I went to see her in hospital, as you know day-hospitals,

but could not even carry a fruit for her or anything to eat. This breaks my heart as I cannot give her anything and she only had the drip on...”

This also increased feelings of helplessness, as the individual could not meet the medical requirements of the care recipient. Participants expressed feeling helpless when they could not maintain the medical and physical care of the PLWHA because of financial constraints. This resulted in the inability of caregivers to take sufferers for regular medical check-ups, as well as not being able to meet their basic daily needs, like providing a nutritious diet. This was expressed as follows;

Ms D said: *“My sister has to go for treatment every month at Grotte Schuur so all the money she is getting ends on transport hired to take her to hospital thus this is impacting on me since she need to go for treatment and I am the only one working...I cannot even go further with my education”*

This placed a greater impact on the family, and resulted in her being unable to continue with her studies. As the only one working in this particular household, she needed to sustain the family by doing part-time jobs. Helplessness not only distresses caregivers when they are unable to meet the medical and physical needs of the care recipient due to financial difficulties, but also when it is a result of emotional difficulties. This is most intense when care recipients present with unusual behaviours.

Mr. H said this: *“One day last month I came back from work and found that the cassette has broken (use of hand-signal to denote head not functioning well-mentally disturbed),I felt so...so (shrug his shoulders and shook his head). I did not know what to do. It was so difficult to see her like that”.*

Discussion

Brouwer et al. (2000) and Flaskerud and Tabora (1998) in their studies also noted that poverty increases the worries of caregivers, as they might not have enough money for a balanced diet and regular medical check-ups - especially when the person is bedridden, as there is a need for transportation to medical facilities. In the present study, it is noted that most of the caregivers and care recipients are unemployed, thus are dependent on social grants e.g. the Child Support Grant or the Disability Grant. Uys (2002) also found that community caregivers reported economic constraints as a challenge to their work.

The care facilities were also far from the caregivers' and care recipients' living areas. Due to the debilitation of the care recipients as a result of the disease, to avoid embarrassment, discomfort and feelings of shame, they needed to use special hired transport. Medical service in South Africa is poor, leading to long waiting periods for ambulances. The emergency facilities use a rating scale (triage) to determine the severity of the condition and how urgent is the case. At times, the sufferer might not be rated as a first priority emergency case, which can be frustrating for the carers who have no medical training. This also increased feelings of distress, as uttered by Mr. A as he waited for the ambulance for almost 5 hours.

Turner, Catania and Gagnon (1994) reported that young adults suffer from opportunity costs of care giving, as these individuals are striving to establish careers and economic security. It was also observed in this study that Ms C had to be a part-time worker as well as a caregiver to a sister in need of care. Because she was unable to continue with studies, there were disruptions for her in task development. This will

literally result in long-term detrimental economic and psychosocial consequences. This also denote the burden of caring, as it impacts on the caregiver's functionality and productivity at work. This is further supported by Turner et al. (1994), who found that those with the poorest financial resources are more likely to perform the physical care activities, as they do not have the ways and means of getting assistance from others.

Helplessness, due to emotional difficulties, is supported in the research of Brouwer et al. (2000), who found that caregivers experience feelings of helplessness, denial and despair. Unlike in their study, where it was noted to happen mostly when the sufferer does not want to eat, in the present study it occurred as a result of the sufferer having cognitive impairment, as sufferers present with mental impairment during the fourth stage. Being challenged with a younger individual who is suffering from memory loss, confusion, and disorientation, makes the carer's life extra difficult and too demanding. Other challenges are around relationship issues.

Edelman (2000) also states that the relationship of the carer and the recipient aggravates the emotional experience of the caregiver. Feelings of helplessness are more intense when the caregiver has been with the recipient for a long time, as being intimate with and knowing him/her as an independent individual increases the emotional intensity.

4.2.1.3 *The Physical Challenge*

Some of the carers reported experiencing physical symptoms as a result of dealing with the HIV diagnosis. One carer expressed having lost weight as a result of not knowing how to deal with the news that his partner is HIV+. This is what Mr. H stated:

“I did not know how to deal with it. I even dropped weight. ...This is not the way I used to be”.

Another carer expressed staying awake at night, thinking a lot about this situation that she is in and how she can enable things to look different. Ms F said:

“...Sometimes I don't sleep because I am thinking the whole night about what am I going to feed these children. I also have sugar diabetes and blood pressure”.

Caring for an HIV/AIDS victim brings up conflicting feelings in the carers. One of those feelings is fear of becoming infected with the virus, thus making the caring process difficult. This fear becomes increasingly overwhelming when an individual is not well informed about how one becomes infected with the virus. Misconceptions about infection are misleading. During Stage III and IV, infected people can have skin problems, leading to open wounds. In this situation, fear was caused by doubts regarding the skin integrity of the sufferer, especially when having to bath them, but not using or having available protective measures, (i.e. gloves). One out of eight carers expressed fears about bathing the sufferer, especially in the presence of open wounds when they don't have gloves to wear - and also when it's not known whether the sufferer has any skin lesions that they might not be aware of. Ms E stated that:

“I at times had fears when washing him especially when I did not see a dent on him but when I know that he have a wound or I have one then I would not feel so terrified, then I will use gloves”.

Others felt that they never kept the diagnosis in mind even when dealing with blood, but were rather concerned about the well-being of the individual. They never even used gloves. This is what Ms G said:

“I never had thoughts of her infecting me; I just think of helping her so that she can get better and do things for herself. Last time at the hospital her drip came out and there was blood running out from her arm, I just wanted to stop the bleeding and when I was about to touch her the sister (Nurse) arrived and said I must stop doing that, I must always use a glove when touching blood”.

Discussion

The theme of physical challenges is supported by Flaskerud and Tabora (1998), who noted that caregivers experienced health problems associated with depression, anger and the number of care recipient's illness symptoms. Being stricken by poverty also increases the symptoms experienced, as the carer also worries about what to feed the sick and vulnerable children under his/her care. Ms F was suffering from loss of sleep, as that was her time to think through her problems, when there were moments of quietness. This theme is further supported by Leblanc, London and Aneshensel (1997), who noted that caregivers reported symptoms of poor physical health that were associated with care related demands and stressors. In this situation the demands of care associated with economic constraints aggravated loss of sleep experienced by Ms F.

Care workers in many studies have reported fear of infection. In a study done by Horsman and Sheeran (1995), results revealed that HIV/AIDS care workers reported fearing of infection. Melnick (2002) also found that caregivers expressed concerns regarding being infected. Contrary to this, the present study revealed the fact that some caregivers never thought of being infected, even when dealing with blood. These individuals were eager to assist their loved ones, hoping for improvement in their health status.

4.2.2 Theme 2: Family and Community Responses

Six questions were asked relating to family and community responses towards the carer and the care recipient. These were aimed at understanding and establishing the psychosocial support networks and strategies available and accessible to caregivers and their care recipients. The carers experienced the family and societal/community responses either in a positive or negative way. Among the six questions there were commonalities that occurred. These mostly revealed the family experiencing emotional turmoil; rejection of the carer and care recipient but mostly for the care recipient and offering of support for both carer and care recipient.

4.2.2.1 The Emotional Turmoil

When caregivers were asked what was the family's response when they first learned about the diagnosis of the other family members, they reported families as having been shocked to hear that their loved ones were living with the virus.

Ms F said: *"She was shocked and said even (Name) and I said yes, even her. She asked, is she alright mentally?"*

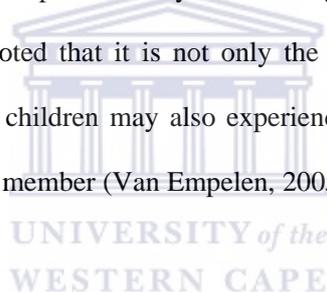
Ms C said: *"they were all shocked, but now they understand".*

Carers expressed that other families were devastated when they first heard about the diagnoses, leading to feelings of denial whereby members will express not disbelief.

Ms D said: *“I did go to my cousin sister...she was so devastated...she said tell me that I am dreaming”*.

Discussion

Emotional intensity is reported to be experienced by sufferers and caregivers, together with their significant others. It is noted that not only the sufferer goes through emotional difficulties, but family members of people infected with HIV/AIDS also experience those difficulties. Bor et al. (1993) supported this theme, stating that stress is seen in families who may respond to the news of the diagnoses with disbelief, shock and confusion. These feelings impact not only on the caregivers but also on the entire family structure. It is also noted that it is not only the family structure that experiences emotional distress, but children may also experience emotional distress due to the HIV infection of a family member (Van Empelen, 2005).



4.2.2.2 Disclosure vs. Non-disclosure

Dealing with HIV/AIDS is not only strenuous to those infected with the disease, but can also be so to those affected by the disease. Talking about it can stimulate the surfacing of either positive or negative responses from those to whom the diagnosis is disclosed. Although the majority of the respondents expressed the disclosure of the diagnosis as being positively accepted by family members, others experienced negative responses following the disclosure. Rejection was experienced, and although this was directed towards the care recipient, it resulted in isolation for the caregiver

and the care recipient as they tried to avoid the family. Fear of infection and death aggravated the negative responses. This led to conflicts within the family, resulting in the carer being emotionally affected. This led to isolation in dealing with the problem, which minimised potential support structures available to this individual.

Mr. H said: *“They reacted so weirdly. I never expected this...they asked me what am I going to do, who is going to look after her and what about the children...what if she dies...we’ve long warned you, you are on your own. I was very upset.”*

In one family, the sufferer was restricted from cooking and playing with the children, as the family was afraid that she might infect them and their children. This increased feelings of helplessness, leading to alienation.

Mr B said: *“My sister was afraid of her, she was so scared such that she used to say to her ‘can you get away from us (her and the children) before you give us your disease, leave the food I will do it myself’. This used to worry her (the recipient) a lot”.*

On the other hand, some of the caregivers encouraged their loved ones to talk to significant others about what they are dealing with to decrease the work-load and emotional distress. Other caregivers felt that it was easier to talk about and accept it when care recipients were openly talking about their illness, which indicated that they have accepted it.

Mr B said: *“they know about her...she talks about it when they come to visit”.*

Ms D said: *‘She talks about it ...she tells people that she is like this because of AIDS’.*

Ms E said: "It's easier to talk about it because she talks about it ... she have accepted it".

Although most of the carers, together with their care recipients were openly talking about living and caring for an HIV/AIDS sufferer, others felt that it was their duty to protect their loved ones, and therefore were not talking about the diagnosis. Caregivers felt that the sufferer needed to be given a space to fully accept the condition, be ready to talk about it. Therefore the carers were only informing significant others and the community surrounding them of opportunistic infections, which the sufferer was experiencing from time to time. Other carers said they feared the responses of other family members and the community at large toward the sufferer, and consequently kept the diagnosis as a secret.

Ms E said: "because he was treated for TB, they knew he had TB only...later he suffered stroke and they knew that as the problem ... I don't want to tell them. I would like him to do that by himself when he feels ready to do it. I don't know how will he react towards me or how will they treat him if they know".

Ms G said: "My sister has her own problems, she is also married with children therefore I don't want to bother her...I don't like my problem to be known by the whole community..."

Discussion

The findings of this research also support the findings of Katz (1981), which connected isolation and rejection, together with subsequent prejudice and discrimination to attributions of stigma. Participants who disclosed experienced

emotional strain, due to rejection of the sufferer by family members. This led them to becoming isolated from their potential support structures.

Participants were fearful and ashamed to disclose what they are dealing with (i.e. the actual diagnosis of the care recipients), as they were afraid of their significant others and the community at large's responses to their problems. Poindexter (2005) also found that caregivers experienced courtesy stigma or associative stigma, resulting in individuals being isolated, hidden, fearful and stressed. Being uncertain about those around them, caregivers resorted to secrecy and defensiveness (Poindexter, 2005). In order to minimise attribution of stigma, some of the caregivers resorted to the use of opportunistic infections as a way to keep the diagnosis a secret to defend themselves and the sufferers. Use of opportunistic infection to keep the diagnosis a secret was supported by several research findings in the field of HIV/AIDS and caregiving (Powell-Cope & Brown, 1992; True Love, May 2002).

Due to the stigma associated with the disease, care recipients were discriminated against. This resulted in feelings of discomfort and uncertainty for the caregiver, as seen with Mr. *B* when his sister rejected and discriminated against their sick sister. He felt helpless and at times hopeless that he is not able to maintain the situation. This was in line with what was observed by Powell-Cope and Brown (1992), who observed that the caregiver and the sufferer are vulnerable to the effects of stigma, such as isolation, emotional turmoil and shame.

4.2.2.3 Offering Support

Carers reported that as the family and the community grew accustomed to having the sick person around them, their response became supportive. Neighbours supported them with eatables, money for transport, cooking, cleaning and making phone calls to arrange for the ambulance, if necessary for the sufferer to be admitted into hospital. Those that had their own vehicles offered assistance with transportation. They even generously offered to be asked for assistance at any time of the day when the carers were in dire need.

Mr. A said: *“They are very supportive...they can assist with anything, when we have no food they will send us food or have no electricity they can buy for us.*

Ms C said: *“they are very supportive, they have even given me permission to wake them up even in the middle of the night...they also help with money and transport”*

Ms G said that: *“there is a lady around the corner who used to come when she is not feeling well and help me to get the ambulance”*

Carers expressed that the families and the communities had a sense of understanding, and also tried to understand the situation from their perspective. Families would enquire about the sufferer with regard to their feelings and the way they were coping with the HIV diagnosis.

Ms C said: *“they understand her now and they are supporting her ...if she is in hospital they will go visit her”*

Ms E said: *“they will visit her, ask her how she is doing and even advised her to take her treatment regularly so that she can get better”.*

Some of the carers felt that the families were caring mostly for the sufferer but minimally for them. Families would visit the sufferers when in hospital, and community members could visit at home and even encourage sufferers to change their lifestyles to live positively.

Ms D said: *“they all gave her words of hope and courage”*

Mr B said: *“There is the other lady who used to come to her, as she (sufferer) was also drinking a lot so as to maybe forget; she used to tell her that “you must stop drinking and look after yourself...”*

Although the communities and the families were giving cognitive as well as emotive support, it was noted that caregivers themselves lacked this, as it was mostly directed towards the sufferer. This in turn increased feelings of helplessness and incompetence in caregivers.

Ms F said: *“They are only helping her, no one has ever asked me how am I feeling but I’m okay with it”*

Mr B said: *“Home based carers are helpful only on her side, there is nothing they can do for us but as long as they are assisting her I am fine with it”*

Mr H said: *“I don’t know where does this come from and no one has ever told me anything... Just happy for those that are helping me”.*

Discussion

Mullan (1998) also correlated instrumental support as a buffer for carers in that, when present, it minimises distress and negative emotional experiences. Unlike in Mullan’s (1998) study where it was observed that instrumental support was lacking for carers of HIV/AIDS, it is noted in the present study that the majority of the caregivers were

instrumentally supported by their families and neighbours in many ways. Families and neighbours offered what was termed *perceived social* support by Schwarzer et al (1994), as their reactions were regarded by the carers as having a sense of understanding and acceptance toward the sufferer.

Sufferers were respected, comforted and given a sense of worth by their communities as well as family members (Hansell et al., 1999).

In most cases the carers expressed having adequate support for the sufferer. They received food parcels, and were assisted with transport arrangements, assisted with cooking, cleaning, bathing and doing the washing. They also expressed feelings of helplessness caused by not knowing how the disease is acquired and not being able to deal with it. This signifies lack of knowledge and information.

Caregivers expressed lack of knowledge and information as well as inexperience in dealing with the ill people, which led to feelings of helplessness. Some felt that the duties of the community care workers were to help the sufferer; hence, they did not have to worry about them. The finding is supported by McCann & Wadsworth (1992), who found that informal carers felt that the care team supported the PLWHA only. Unlike in their studies where there was insufficient emotional and practical support, it is noted that in this study carers had sufficient practical support from their families and communities, with minimal emotional support for carers.

4.2.3 Theme 3: Managing the Role of Caring and Societal Responses

This category theme attempts to elicit the carers' way of dealing with their role of caring, as well as the way the families and society responded to them. The two questions based on this category theme revealed commonalities among the caregivers, and these will be discussed based on the sub-themes of controlling emotions, integrating HIV/AIDS into their lives, turning to spirituality, acquiring feelings of hope and gathering support.

4.2.3.1 Controlling Emotions

Carers expressed having to make themselves strong (i.e. putting on a brave face), especially when in company of the sufferer. They believed that showing real feelings of distress could affect the PLWHA, worsening their (PLWHA) condition. This shows that most of the time, carers were putting the sufferer's well being first, that by controlling their feelings they were protecting them from extra stress, which might negatively affect their state.

Ms. E said: *"I felt so bad, such that I used to cry, but hid myself so that he couldn't see me because he was gonna be worse"*.

Ms. D on the other hand said: *"I am holding on, strengthening myself so that she cannot see that this thing does not feel well for me"*.

Discussion

Several researchers have observed the issue of self-control in care giving. Melnick (2002) found that carers were trying to control feelings as a way of coping. According to Lazarus and Folkman (1989), one factor that influences an individual's coping strategy is self-control. Putting on a brave face and concealing their hurt, anger, disappointment or anxiety helps them to function best. Being in control helped the

care recipients to have hope and courage to persevere under difficult circumstances and to have hope about the future.

4.2.3.2 Integrating HIV/AIDS into Their Lives

As time went on, carers had to accept the illness as part of their daily living and to completely resort to assisting the sufferer to deal effectively with the diagnosis. Some of the carers felt that encouraging and supporting the sufferers to correctly and regularly take their medication was fulfilling for them. Although at times carers felt sorry for the sufferers when experiencing side effects from the medications, thus being tempted to stop the treatment to minimise their misery, some caregivers felt that being the “treatment buddy” to encourage adherence was rewarding. Improvement in the sufferer’s condition brought fulfilment to the carers.

Mr B said: *“to be in her company...I then encouraged her to take her treatment everyday. At times it was difficult, I used to feel sorry for her...I then became strict to her...she is much better now”*.

Knowing what they were dealing with was also fulfilling for caregivers. This helped to minimise the carers’ fears. Accompanying the sufferer for regular check-ups, supporting the sufferer emotionally, physically and socially made caregivers become emotionally stronger for the sufferers, and able to learn from the situation.

Some of the carers found it difficult to accept the sufferer’s condition, and to learn to live with the challenges of the diagnosis, as well as the physical debilitation of the sufferers when they first heard about them having the HIV virus. Feeling sad, hurt, and confused, as well as being tearful and helpless was feelings that clouded

caregivers' attitudes when they first heard of the HIV diagnosis. The caregivers expressed being able to accept the disease when the sufferer had accepted it. This led to feeling free to talk about what they are dealing with, as the sufferers were been open about their disease. This resulted in feelings of relief and acceptance for both the sufferer and the carer. Mr A said:

“She is telling them about her sickness and that made me free to also talk about it to others”.

Ms G on the other hand said: *“She has accepted it, so I also just have to accept it... She talks about it too”.*

In cases where the sufferers had not yet disclosed their status, carers were encouraging them to live openly with the virus in order to reduce the burden. It would also keep them from being overwhelmed by the knowledge of their status without being able to deal with it openly.

This is what Mr. H said: *“I told her that we need to talk about it because people must know what we are dealing with*

For some carers, caring came as no choice to them but they felt that they were *committed* to their loved ones thus had to show respect and give care.

Mr. H said: *“She is my wife; I have committed myself to her so I just have to care for her”*

For some, caring was offered as a way to return the favour to the recipient, as he/she has done so much in the carer's life.

Ms E said: *“I told myself that he's got it... What made me feel OK was that he was always by my side, helped me in many ways.”*

Despite the distress and demands, some of the caregivers, with their family members and the sufferer, *created joyful times* together to create an atmosphere of understanding and acceptance for both the carers and recipients. This was aimed at making the recipients feel accepted and cared for by the family and to understand the dos and don'ts of the disease.

Ms E said: *“Like we (carer and husband) used to take him out, show him how he is supposed to eat and let him do funny things that he enjoys”*

Ms D also said with an ecstatic face: *“she is sometimes so funny you know we used to laugh about it...she would look at herself on a mirror and say ‘I am only bones, shoo I look terrible, don't I?’ She is a very funny person.”*

Discussion

Several researchers have supported integrating the situation into an individual's daily life. Folkman (1997) found that caregivers experience positive psychological states during caregiving and bereavement, with positive reappraisal being one of the coping strategies employed by them. A positive psychological state is associated with searching for and finding positive meaning. In the present study, commitment to caring was associated with commitment in marriage, that is the vows that two individuals made, which meant having to provide care irrespective of the nature of the illness. This involved the activation of beliefs, values or goals that help define the positive significance of the events. It is noted that in the study Mr. H felt that as a married man he vowed to care for his partner irrespective of the situation, and therefore had to stay committed to his vows.

Dorz et al. (2003) found that using denial and humour were associated with emotional exhaustion and depersonalisation. Humour was seen to be an inadequate coping strategy, as it made use of ridiculing, laughing, trifling, and joking about the situation. This was the case with Ms D and her care recipient; although they both experienced humour in a positive way, as a way to ease their minds and to accept the situation, the care recipient depersonalised herself with regard to the way she appeared.

Caregivers also filled ordinary events with positive meaning by creating joyful moments with their loved ones. Caregivers in the study pursued and attained important goals by encouraging recipients to take their treatment, as well as advising them to seek medical advice. Caregiver studies have also revealed that positive effects are related to the use of positive reappraisal, deriving satisfaction from caregiving and problem-focused coping.

4.2.3.3 Spirituality

The caregivers expressed spiritual beliefs and practices either negatively or positively. In a positive way, it was expressed in the form of praying as an individual or with members of the church and/or community, and going to church for spiritual support and giving praises that God has heard their prayers.

Ms F said: *“When I worry a lot I go to church...sometimes I pray by myself”*.

Ms C said: *“I used to pray to God that she must get better”*.

In a negative way, it was noted that carers felt that for their loved ones being diagnosed with HIV was God’s way of testing their faith. Caregivers even asked

themselves questions like, “Why me, God?” which implied the diagnoses were a punishment from God.

Ms G said: *“I wonder what is God doing or maybe He is testing my faith in him”*.

Mr. H said: *“I asked myself why me God...why is this happening to me?”*

Discussion

The use of faith as a coping mechanism has been supported by several studies. Folkman (1997), in her study of gay caregivers’ coping processes, identified spiritual beliefs and practices, which intensified after the partner has passed on. In the present study, spirituality was observed either positively, in the sense that the caregivers were praying for their care recipients’ well being, or negatively, by having thoughts of their faith being tested or it being a punishment from God - hence the question, “Why me, God?”. Melnick (2002), in her study of voluntary caregivers, also identified faith as one of the coping mechanisms employed in the arena of HIV/AIDS caregiving. Catalan et al. (1996), in their study to determine coping mechanisms used by AIDS and oncology nurses and doctors, identified religion as a coping mechanism.

4.2.3.4 Feelings of Hope

Although carers feared death, feeling helpless and having feelings of confusion, there were times when they were hoping for the best; hoping that things will be fine for the sufferers; hoping that one day they will recover and be able to do things for themselves. With the supply of ARV’s, most of the carers felt a sense of relief that the suffering of their loved ones will be over. For those that were fearful of the families’ and society’s response towards the sufferer, for the sufferers to come to terms with the

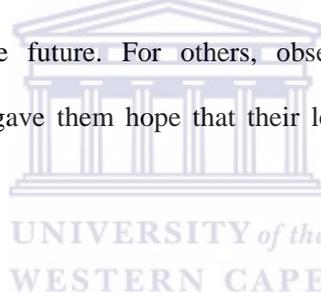
diagnoses and open up gave a sense of hope for the best to them. These were noted from the following:

Ms E said: *“I am now feeling better; I told myself that he is going to be fine. He’s going to have nothing now because he is getting treated and he is also talking about it now”*

Mr. A said: *“I don’t know even myself... I wish that she can succeed only, nothing else”*.

Discussion

Contrary to the study of Brouwer et al (2000), who found that caregivers experienced feelings of helplessness, denial and despair, in the present study it was found that caregivers experienced this at the beginning when they first heard about the HIV diagnoses. When sufferers openly talked about the disease and were on anti-retroviral treatment, they had hope for the future. For others, observing HIV activists successfully living with the virus gave them hope that their loved ones could also succeed.



Rose and Clark (1999) see maintaining hope and optimism as an emotive-focused coping mechanism used to avoid the problem and to deny the facts and implications.

4.2.3.5 Gathering Support

‘Gathering support’ describes the process by which the caregivers sought information regarding HIV/AIDS and care, as well as sought economic, physical, and psychosocial support from family, friends, health care workers and community members. Some of the caregivers disclosed to family, friends and community

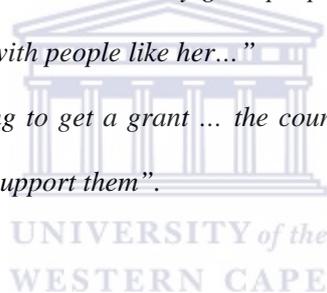
members so that they could be assisted when in dire need. Others needed practical help that involved cleaning, washing, bathing and cooking; requesting their friends and neighbours to assist them minimised the burden. Some of the caregivers joined the home-based care organisation by requesting referrals from the clinic staff so that they could be assisted with care, transport and food parcels for the sufferer and the families.

Mr H said: *“In the beginning I was afraid how people will react... Since I am speaking about it, I’m feeling much better they are supportive... They bring her medication and also advise me on what to do”*.

Ms F said: *“There is a girl in the house behind us whom I always ask to give me help like bathing them, cleaning or even cooking for us when I maybe have to take one of them to the doctor or hospital”*.

Mr A said: *“The home-based carers are very good people to get help from as they are trained in working with people like her...”*

Ms G said: *“I was struggling to get a grant ... the counsellors helped me to obtain a grant to be able to support them”*.



Discussion

It is noted that caregivers in the study used what Lazarus and Folkman (1980) termed a ‘problem-focused coping strategy’. Research found that individuals, when faced with a stressful situation, are inclined to use problem-focused coping rather than emotive-focused coping (Rose & Clark-Alexander, 1999; Lazarus & Folkman, 1980). Individuals in the study bargained and sought social support to be able to cope effectively. Caregivers in the study, as noted especially with Mr. H, said that the caring was overwhelming at first, because they were not openly talking about what

they were dealing with; rather, they saw it as their problem, and were ashamed of what people were saying about them. By openly talking to people, letting them to know and understand what they were dealing with, enabled them to access assistance from others. As men (Mr A & Mr H) with less knowledge about caring, they accessed help and advice in order to be able to deal effectively with the burden of caring. This led to instrumental support from family members and their neighbours in the form of labour work (e.g. bathing, cleaning cooking) or financial assistance (e.g. assisting with applications for grants), which in enabled them to cope effectively.

4.3 Summative Discussion

The relationship between the aforementioned themes will now be explored. It is worth mentioning that the dominant themes together with supporting themes are interconnected. These themes are not remote, but rather each theme enriches the reader's understanding of each other theme.

Caregivers in the study experienced the caring process as challenging and emotionally taxing, although later were able to see it in a positive way. In the beginning, when they first heard of the HIV diagnosis, caregivers went through a series of emotional experiences. Caregivers' experienced emotional ambivalence clouded by feelings of sadness, hurt, shock, unease and emotional confusion. This was later followed by fear of death for their loved ones, resulting in them experiencing multiple losses as a result of HIV/AIDS. Turner and Catania (1997) in their study also found that family members experienced greater subjective strain associated with caring. Unlike the Turner and Catania (1997) findings which found that heterosexual friends were experiencing lesser subjective strain, it is noted that in the present study

the sufferers' partners experienced fear for their own status, which led to emotional confusion. The existence of emotional confusion is supported by Edelman (2000), who construed that caregiving brings feelings of low morale, stress and fatigue. The carers found themselves being preoccupied with the possibility of being positive, which caused fear and negligence of the sufferer.

A study by Mullan (1998) further confirms the fear of death experienced by caregivers as a constant threat leading to feelings of overload, loss and feeling captive to caregiving demands. Some of the caregivers in the study also expressed having the fear of death of their loved ones. Mullan (1997) further reports feelings of guilt associated with caring, whereas caregivers in the present study expressed this less; rather, they expressed feelings of incompetence as they carried on with caring.

Grieving before the actual death occurs has also been supported by research. Carers in the study also experienced what is termed by Keene Reder (2003) as "anticipatory grief". In the present study, the carers' anticipation was based on knowledge of the disease symptoms and progress. The relationship they had with the sufferer influenced the feelings. It is noted that the majority of the caregivers were siblings with the sufferer, with the minority being spouses, children or parents revealing a strong bond between sufferer and carer. Several researchers supported the notion of emotional demands and experiences with regard to caring in the arena of HIV/AIDS (Pakkenham, Dadds & Tarry, 1995; Mullan, 1998).

Participants in the study experienced more than just emotional strain as a result of knowing the sufferer's actual diagnosis. It was noted that financial demands of caring

brought feelings of helplessness. Brouwer et al (2000) and Flaskerud and Tabora (1998) also found in their study that poverty increased the worries of caregivers, as they could not reach their care recipients' health needs. The result of this study correlated with these findings, as the participants expressed their financial challenges. A study by Turner and Catania (1997) further confirms these experiences, as they found that lower income caregivers were more burdened.

Experiencing physical constraints as a result of caregiving demands have already been researched (Leblanc, London & Aneshel, 1997). The result of the present study also suggests that the demands and stressors of caregiving lead to poor physical health.

Emotional difficulty associated with knowing that your loved one is living with the virus was observed not to be experienced by the caregivers only. Participants in the study reported different emotional experiences of the family and the community when they knew about the sufferer's diagnosis. Bor et al. (1993) also found that families may respond to the news of the diagnosis with disbelief, shock and confusion. The present result also supports the notion that these feelings impact not only on the caregivers, but also on the entire family structures.

Difficulties associated with whether to disclose or not to disclose when dealing with HIV/AIDS have been observed by several researchers (Powell-Cope & Brown, 1992; True Love, May 2002). Participants in the study reported experiencing rejection, prejudice, and discrimination, mostly directed at the care recipients by their families following the disclosure (Katz, 1981). Other participants in the study resorted to

blaming the opportunistic infections as the causes of illness in order to avoid humiliation and rejection (Powell-Cope & Brown, 1992).

Although caregivers used opportunistic infection explanations as a way of minimising negative responses, participants in the study observed the family and community responses as positive. The families and the communities offered support to the carers as well as the sufferers. The results correlate to Owens' (2003) findings, which reported that families of HIV positive women gave emotional and concrete support. The present study found that support was mostly offered to the care recipients, and not so much to the carers. A study by McCann and Wadsworth (1992) also found that support from care team members was mostly directed towards sufferers, and less so to carers.

The current study elicited the coping strategies employed by caregivers in the arena of HIV/AIDS. Participants in the study reported controlling their emotions as a way of coping with their knowledge of the disease and the caring demands. Self-control as a coping mechanism was also supported by Lazarus and Folkman (1989) and Melnick (2002). As a buffer, this improved caregivers' self-esteem, which in turn boosted the care recipients' courage and hope for the future.

Other coping mechanisms employed by caregivers included integrating HIV/AIDS into their lives, spirituality, having feelings of hope, as well as gathering support. These coping mechanisms entail what is termed "problem-focused coping mechanisms" (Folkman & Lazarus, 1989; Folkman, 1997; Melnick, 2002). Poor

coping mechanisms used by caregivers in the study included denial and inappropriate humour.

4.4 Summary

The participants' experiences and coping strategies have been described and presented under three dominant themes, namely 'The Caring Experience', 'Family and Community Responses, and 'Managing the Role of Caring and the Societal Response'. The supporting sub-themes under each category were also detailed; lend more meaning and clarity to the participants' experiences and strategies.

These themes were chosen from the data and reflect the essential meanings shared by participants. Direct quotes from participants' accounts were incorporated to provide qualitative descriptions of these themes. The themes were compared to previous research on HIV/AIDS caregivers' experiences and coping mechanisms, and were found to corroborate the majority of the previous research findings. The following chapter summarises the key findings of this thesis. It also further explores their implications for further research, policy formulation and training in the arena of HIV/AIDS. Lastly, recommendations for future research will be addressed.

CHAPTER 5

CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

This chapter concludes the thesis by summarising the key research findings. The aim of the thesis was to explore the psychosocial experiences of HIV/AIDS primary caregivers, and to understand the coping strategies employed by these caregivers to deal with their own feelings as well as the responses of the public towards them. It has been argued throughout this thesis that the lived experience and coping strategies of caregivers, specifically informal caregivers, is of primary significance. Their study is of great importance if one is to gain an in-depth and broad understanding of the caring of sufferers in the arena of advanced HIV/AIDS disease. Previous research findings can be seen as relevant in that they reveal the psychosocial experiences of caregivers, but they do not address the lived experiences and coping strategies of HIV/AIDS primary caregivers.

5.2 Summary of the Key Findings

A thematic content analysis was used to describe the psychosocial experiences and coping strategies of HIV/AIDS primary caregivers. These findings were presented as three main themes, namely; 'The Caring Experience', 'Family and Community Responses', and 'Managing the Role of Caring and the Societal Response'. Participants described caring as a challenging process, experienced in both positive and negative ways. The caring experience was found to be an emotionally ambivalent situation, where participants experienced feelings of shock, hurt, confusion, sadness and helplessness, as well as suffering multiple losses.

Participants further expressed experiencing financial challenges as a result of caring demands, because they were not employed, thus depending on grants. As a result of the strains experienced by caregivers, some of the participants expressed experiencing physical symptoms due to caring demands. With regard to family and societal responses, caregivers also observed that families and society experienced emotional turmoil when first hearing about the diagnosis. Although these feelings were apparent, some of the caregivers had found it difficult to disclose what they were dealing with as a result of being ashamed of what the responses could be towards them –and especially towards the sufferers.

Some of the participants expressed using opportunistic infections that the sufferer was suffering from, like TB, Meningitis, pneumonia, and strokes as the causes of illness. Those caregivers that disclosed to their families experienced rejection and hostility from family members, which was mostly directed towards the sufferers. This resulted in feelings of discrimination and isolation for both the sufferer and the caregiver. Furthermore, participants told of being offered support by family members and society in the form of “instrumental support” i.e. bathing, feeding and supplying transport for the sufferer, together with emotional support, which was mostly directed towards the sufferers.

The study further reveals that participants experienced little or no emotive and cognitive support from family, society, nor the community health workers who were visiting the sufferers at home. This led them to feel more helpless, leading to the use of poor coping mechanisms. Regarding the participants’ way of managing their own experiences and feelings, as well as the way society and families responded to them,

some of the caregivers spoke of controlling their emotions, especially when in company of the care recipient, in order to protect the sufferers and them cope better with the disease.

Caregivers further expressed integrating the disease into their daily lives by accepting the sufferers' condition as being real and existing, and by creating joyful meaning for the sufferer and other family members, and by fulfilling their commitments to the sufferers. Use of spirituality, in either a negative or positive way, was also experienced. Some of the caregivers expressed going to church, and praying with other family members and the community for the well being of the sufferers. Others expressed questioning God with regard to their loved ones being infected with the disease, and saw the disease as a punishment for them from God.

Participants also expressed having feelings of hope, especially with the introduction of anti-retroviral therapy as part of the disease management for their loved ones. They hoped for better results from the treatment for the sake of the sufferer, as well as for the benefit of the sufferer's children. Caregivers further expressed gathering support from other family members and health care workers to be able to deal with the disease's demands actively.

The findings of this research are relevant as they supplement previous research on psychosocial needs and demands of HIV/AIDS informal caregivers, providing the experiences and coping strategies of primary HIV/AIDS caregivers within the South African context. It is suggested that caring within the HIV/AIDS arena can be emotionally challenging, and that caregivers within this context still experience HIV

related stigma, leading to nondisclosure. And where the disease is disclosed, carers and sufferers experience discrimination, resulting in isolation, which later results in the use of poor coping mechanisms. The results further suggest that although there was emotional and cognitive support, it was mostly directed towards the sufferers, with minimal support for the carers. In summary, the participants' experiences and coping strategies were found to support and supplement the findings from previous research on HIV/AIDS primary caregivers' subjective and objective experience, thereby adding new insight and meaning.

5.3 Implication for Future Research and Recommendations

The thesis results substantiate previous research by providing rich, in-depth descriptions of how previous findings are subjectively experienced by HIV/AIDS primary caregivers. This has important implications for future research on HIV/AIDS primary caregivers. This study shows that caring for an HIV/AIDS individual can be emotionally, physically, socially and economically demanding. The study further sheds light on the minimal support structures available to caregivers, resulting in poor coping mechanisms, which can lead to increased stress and can result in physical and emotional burnout. It is therefore recommended that future research explore these caring demands to provide additional insight and understanding of the primary caregivers of HIV/AIDS, specifically among young adults.

The researcher further recommends that trained caregivers working within the arena of HIV/AIDS caregiving be equipped to be able to apply the *Triad Model*, whereby the sufferer and his/her caregiver is emotionally and physically assessed in order to combat burnout. Home-based carers must be able to define for themselves what is

personally meaningful and of value to the caregivers, facilitate intimacy and conversations between caregivers and their care recipients to be able to disclose to other family members. Other recommendations include training home-based carers to be able to assess stress-related symptoms among caregivers and to refer accordingly. Future policies must also be developed to accommodate this minority group that is not well understood. Identifying difficulties and the resources that impact in the individual experiences of caregiving, both in the families themselves as well as in the larger sociocultural context, is valuable as a guide for the development of family interventions tailored to the specific needs of the different family subgroups. These interventions could support the diversity of families living with HIV/AIDS, and also help sustain families in their important and challenging caregiving task.

5.4 Limitation of the Research

The participants in this research were mostly siblings of the sufferers. However, most of the sufferers of HIV/AIDS might have lost partners due to infection, or had broken the relationships off as a result of the diagnosis. It would be of great importance, as well as being informative, to explore the experiences and coping strategies of partners who are caring for their infected partners, as it was noted that men in the study were observed to have more caring burdens in comparison to the female caregivers. These burdens were mostly associated with the instrumental care of the sufferer, especially with regard to daily activities, e.g. when sufferers were unable to bath themselves or walk to the toilet.

In this research, the caregivers were exclusively interviewed, and not the sufferers. Several researchers around the world have explored the impact of caring by looking at

both the sufferer and the caregiver, providing more insight into their feelings and reactions to each other. This was not explored in the present study, but could prove an interesting future research topic. The researcher further acknowledges that her perceptions and views have influenced the research process, particularly the data analysis. It is also noteworthy that due to this research being qualitative in nature, her inferences and interpretations as the researcher are essential parts of this thesis.

5.5 Conclusion

In conclusion, this thesis describes the subjective experiences and coping strategies of HIV/AIDS primary caregivers. Semi-structured interviews were employed to collect data, which was analysed using the thematic content analysis. The results of the participants' experiences and coping strategies consisted of four dominant themes, which contained the essential meanings of participants' accounts. The results suggest that caring for an HIV positive individual can be emotionally and physically draining, but later can be fit into one's daily lifestyle. It can lead to prejudice and stigma from those that could potentially offer support to the sufferer as well as the carer, causing strain. The findings of this research strongly support previous research and sheds light on issues that were observed positively as being negatively observed. This thesis suggests that more training and education is needed for the caregivers, and therefore professional caregivers need to be equipped to be able to assess the signs of burnout among HIV/AIDS primary caregivers. The study adds to the body of knowledge, which can inform policies and training in the HIV/AIDS arena.

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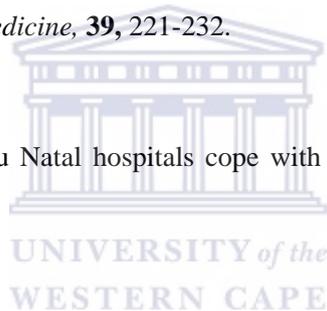
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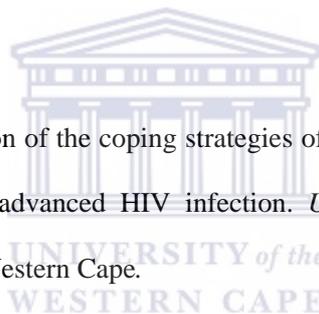
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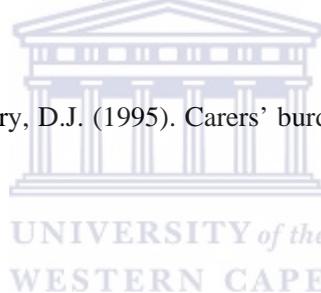
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APPENDIX A

INTERVIEW GUIDE

1. Gender: M/F
2. Age
3. Are you employed?
4. How many people are living in the house?
5. Who is the breadwinner?
6. What is the total income of the household?
7. Age of the person that you are caring for.
8. How are you related?
9. Was s/he employed prior to the illness and if yes, what kind of a job was he/she doing?
10. For how long have you been caring for this person?
11. To your understanding what is wrong with the person that you are caring for?
12. For how long did you know about this?
13. If you can still remember, when you first heard about his/her illness how did you feel/react to the news then?
14. For how long did you have this kind of feeling and how did you relate with the sufferer during that period?
15. Looking back at the day you first heard, (reflection on what is said at no. 13) the kind of feeling and reaction you had how could you describe the way you are feeling now/presently?
16. From the time you heard up till today how did you deal with what you were feeling to come to the stage that you are at currently?
17. Do other members of the family (immediate) know what is the person suffering from and did you/sufferer inform them? (If not informed by you/sufferer, why not?)
18. How did they react when they first heard about this?
19. How are they dealing with it now?
20. Do your neighbors as well as other community members know about the person's condition?

21. How did they get to know about it?
22. Do you perhaps speak to them about your experiences and how do they react towards you as well as to the person that you are caring for?
23. How do you deal with the way your neighbors react towards you?
24. When he/she is very ill to such an extent that she needs total care, how do you feel during that period?
25. Do you have any source of help and from whom are you receiving this help?
26. How do they assist you?
27. Do you find this helpful towards your emotional as well as physical feeling?
28. If you were to suggest/ask for any form of help what would that be & why?
29. Have you ever had fears of being infected especially when the person is bleeding/vomiting and how do you deal with it?
30. Are you married/intimately involved?
31. How does his/her current situation affect you affair and how do you deal with that?



APPENDIX B

To whom it may consent as research participant

Dear Participant

I am Molemoeng M Shebi currently studying a Masters Degree at the above university within the Department of Psychology. I am interested in doing a study on Experiences and Coping Strategies of HIV/AIDS Primary Caregivers within the two disadvantaged communities in the Western Cape Metropole (Guguletu & Khayelitsha). The aim of the study is to capture the lived experiences of caring for an ill person as well as how do you deal with these experiences. In order for my study to be successful, your participation will be highly appreciated.

Terms and conditions of the agreement

Should you agree to participate in the study please note the following:

- a) Your participation is voluntarily
- b) The interview will be conducted with respect for your privacy
- c) Your information will be treated with confidentiality
- d) You will remain anonymous (i.e. your name will not be mentioned to anyone)
- e) You are free to withdraw from the study anytime should you feel uncomfortable
- f) The interview will be audio-recorded for analysis purposes but at no point in the transcription will you be identified.
- g) The information obtained will be used for research purposes only
- h) All information will be kept secure by the researcher at all times.

Thank you for your participation.

Molemoeng Shebi

Signature (Participant)

I agree/do not agree to participate within the study

Witness _____