The Resilience of Caregivers at a Gauteng-based Hospice with Patients Living with HIV/AIDS

BY

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ABSTRACT

This study investigates the resilience of caregivers at a Gauteng-based hospice with patients living with HIV/AIDS. The primary focus of this study was to describe the impact on caregivers working with terminally ill patients predominantly with HIV/AIDS. Six participants were selected for this study utilising purposive sampling. Their ages ranged between 30 and 70 years. For the purpose of data collection, face-to-face semi-structured interviews were undertaken. In analysing data, the themes and sub-themes were extracted and presented by employing thematic analysis. The findings of this study revealed that in times of adversity and setbacks most caregivers utilise various skills to bounce back, and they still showed contentment in serving community members. However, caregivers have also voiced the concern that the support offered at work was not sufficient in meeting their needs. Recommendations for further research, on the resilience of caregivers when working with terminally ill patients is highlighted.

Keywords: caregiver, HIV/AIDS, hospice, resilience, thematic analysis

ACRONYMS AND ABBREVIATIONS

AIDS   Acquired Immune Deficiency Syndrome

HCBC   Home and Community-Based Care

HIV   Human Immunodeficiency Virus

HSRC   Human Sciences Research Council

PLWA   People Living with HIV/AIDS

PROQOL   The Professional Quality of Life Scale

UNIAIDS   The Joint United Nations Programme on HIV/AIDS

USA   United States of America

USAID   United States Agency for International Development

WHO   World Health Organisation

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CHAPTER 1

BACKGROUND OF THE STUDY

Introduction

Research Context

There is great concern that even though caregivers take care of patients, they also experience personal challenges such as health, stress or depression. As noted by Morse, Shaffer, Williamson, Dooley and Sculz (2011), caregivers face greater physical illnesses, stress and "poor" health problems. Morse et al. (2011) further states that relationship attributes have been related to greater caregiver depression, burden, and providing problematic care. The aim of this chapter is to provide the outline of this study by focusing on the statement of the research problem, significance of the study, definition of concepts, research aims, research question, and the basic structural outline of the study.

Research Problem

Gass-Sternas (1995) is of the view that research is needed to develop a strong knowledge base from which to develop health interventions. The review of literature indicated that, to date, no specific research has been published on resilience of the caregivers of the hospices caring for patients affected by HIV/AIDS within the South African context. This research aimed to investigate the experience of caregivers in working with terminally ill patients, the focus on workers in particular. Furthermore, the research aimed to explore feasible ways that assist caregivers to educate and empower themselves with coping skills holistically when faced with adversity.

A number of international studies have been done on resilience of caregivers. However, little research has been done within the South African context. Grotberg (2004)

maintains that much has been done to address children with special needs and this has been a critical part of concentrating the world's attention on the problem. South Africa is currently faced with many individuals who are vulnerable in one way or another, including: physically, emotionally, socially, financially and relationally (Ferreira, 2008; Loots, Ebersőhn, Ferreira & Eloff, 2012; Meintjies, 2009; Motha, 2010; Smit & Fritz, 2008). De Chesnay and Anderson (2008) postulate that some members of society who are not members of the culturally-defined vulnerable populations may be vulnerable only in certain contexts. For example, employees who work with ill people and visitors are vulnerable to infections, or day-care providers are vulnerable to a host of communicable diseases because of their daily contact with patients.

Significance of the Study

Working in a community-based placement made the researcher realise that being in a good state of mind is not only relevant to the patients but it is also about recognising those who care for them, a lack of which could cause shortcomings. This may subject them as workers to mental abuse such as discrimination (Shelton, 2003).

Seligman (2002) believes that resilience exists when people are optimistic, have a sense of adventure, courage, and self-understanding, use humour in their lives, have a capacity for hard work, and possess the ability to cope with and find outlets for negative emotions.

In addition, Glicken (2007) indicated the following individual factors that reduce the risk of stress: an easy-going disposition, a strong self-esteem and sense of identity, intelligence, physical attractiveness, as well as supportive friends and loved ones. Previous research has maintained a predominantly quantitative focus with regard to the experiences of caregivers. Deacon, Stephney and Prosalendis (2005) indicated that methodologically, instead of relying only on self-reporting of stigmatising attitudes and intended discrimination in

surveys "we need to use more participant observation and detailed analysis of interviews" (p. 55). Consistent with recent studies such as volunteer stress and coping in HIV/AIDS home-based care conducted by (Moremi, 2012), this research study saw the need for the study to be conducted qualitatively in order to allow caregivers to explore their daily experiences in caring for patients living with HIV/AIDS. In addition, the study allows an in-depth understanding of the phenomenon of resilience.

This study was also relevant in that the caregivers' voice and opinions need to come to the fore as personal views are not often researched. Consistent with Setswe, Davids and Human Sciences Research Council (2009) community home-based care has psychological, social, economic, physical needs which need to be met to enable caregivers to do their care-giving work, effectively. However, most of the attention to caregiving and providing services has been for children (Grotberg, 2004). The researcher desires that the current study should elicit interest among potential researchers to further investigate the resilience of caregivers in working with terminally ill patients.

Definition of Concepts

Resilience

Resilience has been defined as "the process of adapting well in the face of adversity, trauma, tragedy, or even significant sources of stress such as family and relationship problems, or workplace and financial stressors" (De Chesnay & Anderson, 2008, p. 42). Other descriptions include "the ability to 'bounce back' in spite of significant stress or adversity" (Place, Reynolds, Cousins & O'Neill, 2000, p. 162) and the ability to "spring back".

Henry (1999, p. 521) defines resilience as "the capacity for successful adaptation, positive functioning, or competence despite high risk, chronic stress, or prolonged or severe trauma. Glicken (2007) indicates that resilience may be seen as the ability to readily recover

from illness, depression, and adversity. In addition, Walsh (1998, p. 45) maintains "we cope with crisis and adversity by making meaning of our experience, linking it to our social world, to our cultural and religious beliefs, to our multi-generational past, and to our hopes and dreams for the future". Resilience is an active process of endurance, self-righting, and growth in response to crisis and challenge. Resilience entails more than merely surviving, getting through or escaping a harrowing ordeal. In contrast, the qualities of resilience enable people to heal from painful wounds, take charge of their lives, and go on to live fully and love well (Walsh, 1998).

Caregivers

According to the Stevenson (2010), a caregiver is a person who takes care of a sick or old person at home. However, in the study conducted by Gahagan, Loppie, MacLellan, Rehman and Side (2004), caregiving is much more than simply attending to the physical needs of a recipient. Caregivers have multiple roles and responsibilities, including advocating on behalf of themselves and the recipients, ensuring that recipients are treated with respect and dignity, and that as far as possible, and recipients have been given the opportunity to give input into decisions concerning their care.

The Joint United Nations International Programme on HIV/AIDS (2000) states that community care programmes for people with AIDS are mostly run by volunteers. Some are informal volunteers, friends or neighbours who care for sick people or church members. However, great numbers of people working for AIDS care programmes are formal volunteers recruited, trained and supervised by the organisations they work for.

Hospice

A hospice is a programme of supportive services for terminally ill patients and their families, provided either at home or in designated in-patient settings, which are purported to improve patient and family quality of life at lower cost than conventional terminal care. A

hospice is both a philosophy and a system of terminal care. As a philosophy, it reflects late-twentieth-century Western cultural and social values. It confronts the dying process openly and prepares people to experience dying as an inevitable, natural phase in the life cycle (Birnbaum et al., 1985). The hospice movement emphasises palliative rather than curative treatment, quality rather than quantity of life. A typical hospice team includes a physician, a nurse, a home health aide, a social worker, a chaplain and a volunteer. The team assists the patients to live out their final days. Although some patients are cared for in their homes, the hospice also provides care to patients in their inpatient institutions.

HIV/AIDS

Briefly, "Acquired Immune Deficiency Syndrome (AIDS) is a clinical syndrome associated with HIV infection, and is diagnosed when there is evidence of severe immuno-suppression in an HIV-infected person (defined by a CD4 T-lymphocyte count of less than 200 cells/mm3 and laboratory evidence of HIV infection of less than 14% of total lymphocytes) or the presence of an AIDS-indicator disease (candidiasis of the oesophagus, trachea, bronchi or lung; invasive cervical cancer; extra-pulmonary coccidiomycosis pulmonary tuberculosis, recurrent bacterial pneumonia, or invasive cervical cancer" (Boswell, 2009, p. 87).

Research Aims and Objectives

The Aims of the Study

- To explore the experiences of the caregivers when working with HIV/AIDS patients who may be stigmatised;

- To establish the nature of interventions provided for caregivers at their workplace and whether those interventions cater for their needs;

- To provide a comprehensive picture about the experiences of the caregivers of the hospice working daily with HIV/AIDS patients;

- To draw out the caregivers' insights regarding looking after their own emotional, physical and social well-being;

- To provide a platform to the caregivers to have a voice with regard to their issues of concern.

Specific Aim

This study will explore how the hospice's caregivers perceive themselves as working with terminally ill patients, especially those infected with HIV/AIDS. This study seeks to expand on the stories of the employees of a South African hospice and to ascertain how they feel and cope when working with dying people.

Research Questions

The current study poses the following research questions:

- What are the experiences of the caregivers working with terminally ill HIV/Aids patients? (Armstrong, 2000).

- To what extent are caregivers who look after HIV/AIDS patients resilient? (Mignone et al. 2011).

- Where do they draw their strength in times of distress? (UNIAIDS, 2000).

- What does it mean for the caregivers to work in an environment where patients die regularly? (Shaller, 2007).

- How do caregivers perceive themselves within their working context? (Reinhard, Given, Petlick, & Bemis, 2008).

Research Method

This study utilised a qualitative method of inquiry as it was considered appropriate to comprehend the resilience of caregivers at a Gauteng-based hospice with patients living with HIV/AIDS. Semi-structured interviews were conducted to encapsulate the caregivers' discourse.

Outline of Chapters

The study consists of the following chapters:

Chapter One: This chapter introduces the topic of this dissertation and it comprises a statement of the research problem, definitions of the concepts, research aims and objectives, research question and method.

Chapter Two: The chapter reviews the literature available and related to the current study as well as the theoretical framework that informs this study, namely, Urie Bronfenbrenner's ecological perspective.

Chapter Three: The chapter will comprehensively elaborate on the research method utilised including the research design, data collection method, data analysis, and ethical considerations.

Chapter Four: In this chapter the findings of the study will be discussed in detail. The themes extracted from the raw data will also be explored and linked with the relevant literature.

Chapter Five: This final chapter presents an overview of the study, the concluding remarks pertaining to the study, the limitations of the study and future recommendations.

CHAPTER 2

LITERATURE REVIEW

Introduction

The current chapter explores the resilience of the caregivers when working with terminally ill patients across a broader spectrum of cultures, that is, internationally and in the South African context. The chapter also unfolds the theoretical framework that informs this study by drawing on Bronfenbrenner's (1979) ecological perspective.

Most of the attention to caregiving and providing healthcare services has been for children and youth, and also much has been done to support children with special needs (Grotberg, 2004). For example, DePanfilis (2006) argues that child protective services are at the centre of every community's protective efforts. Furthermore Hill, Stafford, Seaman, Ross and Daniel (2007) explain that when people experience any active adversity they are especially in need of resilience-protecting factors. Researchers of the Cantwell (2006) interested in the psychopathological development of children have emphasised the importance of studying both children who suffer from adverse outcomes and those who display various risk factors as such comparisons can enhance our understanding of normative and atypical development during different phases of the lifespan.

Gaugler, Mittelman, Hepburn and Newcomer (2009) claim that psychiatric morbidity associated with caregiving, has largely focused on caregivers of patients with dementia, and with a handful of studies concerning other illnesses. The researcher's focus in the current study will be to understand the caregiver's experience of assisting adults living with HIV/AIDS.

Resilience is viewed in terms of the interplay between multitude risk and protective processes over time involving individual, family and larger socio-cultural influences, with

chronic medical illness or recovering from catastrophic life events and loss of mind (Gaugler et al., 2009).

As noted by Black and Lobo (2008), resilience entails more than surviving a crisis, but also offers the potential for growth out of adversity. It is important to note that working in a context of people often dying may affect caregivers within their family life. After all, problems are seen as resulting from an interaction of individual and family vulnerability in the impact of stressful life experiences and social contexts (Walsh, 2003). The focus of the current study will be to explore how caregivers perceive themselves in working with the terminally ill, especially those infected with HIV/AIDS. The study also seeks to expand on the stories of the employees of a South African hospice and to ascertain how caregivers feel and cope when working with dying people.

An Overview of Resilience

The main focus of resilience has been on children and adolescents (MacDermid, Samper, Schwarz, Nishida & Nyaronga, 2008; Schmied & Tully, 2009). However, as stated by Zauszniewski, Bekhet and Suresy (2010), interest has emerged in viewing resilience in diverse contexts such as incorporating areas where adults, families and broader society are concerned.

The concept of resilience was originally described in the 1950s, and research regarding the concepts of vulnerability, coping and stress resistance has been pursued in the fields of positive psychology, health psychology, psychopathology and developmental psychology (Sun & Stewart, 2007).

Resilience, according to Chen (2012), has become significant through the studies of risk to understand how children cope in the face of adversity. Research on resilience has been widely studied in the disciplines of: psychiatry, psychology, sociology and biology (Greeff,

2007). Resilience studies began with focusing on within-person factors as opposed to considering other contexts of adaptation (Chen, 2012; Waller, 2001). As the work in the field of resilience is developing, there has been a shift from viewing resilience individualistically to viewing it collectively (MacDermid et al., 2008).

Resilience and functioning concepts argue similar notions in terms of the human bodily system's adaptation and dynamic processes when confronted with stress. Resilience is a resource for conquering difficulties, because resilience often manifests in individuals as tranquillity, hope and a positive outlook. Similarly, Woodgate (1999) explained resilience as an active process that develops internal resources for coping with stress. Weathering a crisis together, a family can emerge more loving, stronger, and more resourceful in meeting future challenges (Walsh, 1998; White, Richter, Koeckeritz, Munch & Walter, 2004). Therefore, an optimistic confidence in overcoming the odds lies at the heart of resilience.

Resilience Factors

Risk, Protective and Recovery Factors

Researchers on resilience describe it as having a dynamic interaction between risk and protective factors (Loots, Ebersőhn, Ferreira & Eloff, 2012; Zauszniewski et al., 2010). McCubbin and McCubbin (1993) view these factors as working interchangeably to respond successfully to crises and challenges. While risk factors are related to any event or experience that enhance the probability of undesired outcomes, protective factors act as buffer to negative exposures (Chen, 2012).

Protective and recovery factors are regarded as the dual functional nature of resilience. They are deemed to facilitate adjustment or the ability to maintain integrity and functioning, and to fulfil developmental tasks (Black & Lobo, 2008). Strauss (2011) revealed that the protective function of resilience relates to the ability to endure or survive the

onslaught of events, which are normative and consequently related to normal life-cycle challenges.

Risk factors are identified primarily by chronic adversity in the environment of an individual. Waller (2001) describes risk factors as influences that occur at any systemic level, that is, at individual, family, community or society level that threaten positive adaptive outcomes. While Rutter (1987) maintains that risk factors are hazards relating to the individual or to the individual's environment that increase the likelihood of a problem occurring. Risk factors are thought to be associated with later psychosocial problems such as substance abuse or dependence.

Acute stressors are considered the stimuli for disruption and integration thus beginning the resiliency process (Kumpfer, 1999). The environmental context of stressors and supports can help the individual through psychosocial facilitation processes. Therefore risks have remained a particular focus in order to identify the resilience processes and factors at work. The presence of risk factors are also needed to give rise to the onset of protective and recovery functions in resilience, for example, financial difficulties, interpersonal strain and substance misuse (Strauss, 2011).

Hawley and De Haan (1996), and Rutter (1999) suggest that risk factors are often prevalent. McCubbin, McCubbin, Thompson, Han and Allen (1997) emphasise that protection factors are key. McCubbin and McCubbin (1996) view recovery factors as important. Antonovsky and Sourani (1988), McCubbin et al. (1997) and Walsh (2003) maintain that risks remain pivotal in strengths-based studies of resilience, a focus on various factors and processes, such as resources, meanings attributed to the stressor and communication patterns are a significant feature of further developments in resilience research.

Resilience in the South African Context

Various themes characterise these experiences of resilience which include professional roles, personal skills and qualities, gender and race and family dynamics. Work experience plays a major role in an individual's choice to be a caregiver, that is, most of the hospice employees have worked in the medical setting before, for example, as auxiliary and professional nurses.

For example, Van Breda (2001) conducted a study on nurses which revealed that they have a sense of coherence which assisted them in coping with the juggling of work and family responsibilities and in coping with occupational stressors. Lee et al. (2003) contend that nurses could help families and individuals to maintain balance and functioning when the family is confronted with crises such as chronic illness, for instance HIV/AIDS.

Resilience involves the potential for personal and relational transformation and growth that can be forged out of adversity (Walsh, 2003). The care for people living with HIV/AIDS is seen as placing a significant burden on caregivers due to the escalation of the epidemic in sub-Saharan Africa (Lwelunmor, Airhihenbuwa, Okoror, Brown & Belue, 2012). Fox, Fawcett, Kelly and Ntlabati (2002) state that the influx of patients can influence the quality of care provided as hospitals have become crowded as a result of AIDS patients who outnumber patients with other illnesses.

Researchers in South Africa such as Majaja et al. (2000) have recognised that more families are affected by the insurmountable rate of the HIV/AIDS burden. Consequently, there was an increasing need for containment and support. The government and non-governmental organisations developed such projects to cater for psycho-social support, economic support and home-based care. Aggleton and Warwick (1999) emphasise that information regarding the most effective ways of working is of vital importance if countries are to be helped to develop HIV prevention and care programmes that really work. As argued

by Songwathana and Manderson (1998), AIDS may be perceived as a plague or punishment from God or bad luck in African social or cultural contexts.

Furthermore, Songwathana and Manderson (1998) noted that lay persons and health care professionals often have different models, particularly when patients and health professionals are from different cultural backgrounds and this is seen as an obstacle in healthcare delivery. It is pivotal to understand the ways in which the lay explanatory models are elaborated as it may assist in the negotiation of differences and in the effective development of public health education programmes related to AIDS. For some South Africans HIV/AIDS is perceived as a disease without cure and a disease of promiscuity (Setswe et al., 2009).

People sometimes respond to HIV/AIDS patients with fear and anxiety especially because effective treatment is not yet guaranteed. Some patients perceived that once diagnosed with the disease, the destination is death. Many people from various cultural groups, particularly black South Africans, opt for training as traditional healers as they believe the sickness has to do with ancestral calling. According to Lwelumnor et al. (2006) the treatment outcome varies as some people obtained help while others perpetuate the condition as they take African herbs and reject the use of Western medicines.

Fox et al. (2002) maintain that various factors such as poverty and isolation, hunger, fear for the future of their children, difficulty accessing grants, lack of male participation in HIV/AIDS services, unsympathetic health and social service workers, were identified in a study conducted in South Africa in relation to the needs of people living with HIV/AIDS. These are needs that can be addressed through a home-based care programme. It is for these reasons that the caregiver's intervention of educating the patients and their significant others plays an important role (Fox et al., 2002).

Impact on Life and Significant Others

Walsh (2007) showed that serious individual and relational distress can occur together with: anxiety, depression, substance abuse, violence and estrangement. That is, loved ones often suffer from secondary traumatisation and compassion fatigue. The impact of the HIV/AIDS epidemic on individuals, households, family and friendship networks is deemed to be serious (Aggleton & Warwick, 1999).

UNIAIDS has been concerned to support both through the work of its co-sponsors and through the efforts of community groups and organisations. Naidu (2005) indicated that caregivers usually deal with issues relating to personal identification with the disease, patient, family problems and negative community perceptions, fear of infection and burnout.

Working with terminally ill or dying patients may be traumatic and overwhelming and may cause caregivers experience pain and fears similar to those of their patients (Reinhard et al., 2008). Depression, despair and cynicism, alienation from friends, families and colleagues, professional impairment, physical and psychological impairment are some of the effects experienced by caregivers. In addition, Reinhard et al. (2008) argue that caregivers are hidden patients themselves with serious adverse physical and mental health consequences from their physically and emotionally demanding work as caregivers and reduced attention to their own health and health care.

Ways of Coping in Times of Adversity

Part of the context of the hospice being researched in the current study includes spirituality. Walsh (1998, p. 45) maintains that "we cope with crisis and adversity by making meaning of our experience, linking it to our social world, to our cultural and religious beliefs, to our multi-generational past, and to our hopes and dreams for the future". Caregivers require a number of self-care and coping strategies, including having supportive relationships and making time for humour, spirituality and leisure activities (Gahagan et al., 2004).

From a South African perspective, Van Dyk (2012) emphasises the importance of Home and Community-Based Care (HCBC) programmes as a way of providing the organisational structures, resources and framework that will enable the caregivers to look after their own sick members. She has also highlighted its functions as empowering the community and the family to cope effectively with: the physical, psychosocial and spiritual needs of those living with HIV infection and AIDS.

When confronted with problems, many individuals foster an optimistic attitude with spirituality, seeking purpose in faith. Black and Lobo (2008) argue that a shared belief system of hope and triumph enables individuals to make sense of crises or change. Fundamental family beliefs are founded in religion and spirituality. Spirituality has been found to be an essential factor in resilience, as it provides families with the ability to unite, understand, and overcome stressful situations (Black & Lobo, 2008).

Kumpfer (1999) highlights spirituality as the major predictor of resilience, while it has been highly predictive of positive life adaptation. Strauss (2011) claims that during loss of life or significant material possessions, spirituality enhances meaning and justification for the survivors. A study conducted by Gahagan et al. (2004) indicates that participants often turn to spirituality as a source of inner strength especially in challenging situations. It is crucial to understand the individual's belief system, which is rooted in cultural and spiritual traditions and influences their perceptions and coping responses to traumatic experiences (Walsh, 2007). Incorporating religious and spiritual practices as part of coping behaviours has been shown to assist in the management of distressing events (Strauss, 2011).

According to McCubbin et al. (1997) the maintenance of a sense of hope is vital for a resilient outcome and successful adaptation. In times of deepest despair, hope is most essential for recovery (Walsh, 2007). As noted by Zauszniewski et al. (2010) hope is created from memories and is influenced by relationships with others which promotes forward

movement and provides new insights and a sense of purpose. Hope fuels energies and emotional investment of individuals to rebuild lives, revise dreams, renew attachments and create a positive legacy to pass on to future generations (Walsh, 2007).

Seccombe (2000) suggests that resilience cannot be understood or improved in significant ways by merely focusing on the individual-level factors. Instead, careful attention must be paid to the structural deficiencies in societies and to the social policies that systems need in order to become stronger, more competent, and better functioning in adverse situations. Resilience involves mastering the possible, coming to accept what has been lost and cannot be changed, while directing efforts to what can be done and seizing opportunities for something good to come out of the tragedy. In the wake of devastating trauma, individuals can be helped to regain hope in their future possibilities (Walsh, 2007).

According to Walsh (2002), mental health professionals can create a safe haven for family and community members to share both deep pain and positive strivings. Therefore the need to co-create context is crucial in order to allow patients to vent their concerns and frustrations.

The Role of Caregivers

Caregivers are deemed to represent an important network of people who struggle to meet the daily needs of HIV-infected individuals (Theis, Cohen & Zelewsky, 1997). Caregivers co-ordinate a threefold relationship between patient-care recipient, the formal or professional caregivers and the informal primary caregiver. Reinhard et al. (2008) are of the view that caregivers spend a substantial amount of time interacting with their care recipients while providing care in a wide range of activities. Raveis and Siegel (1991) outline the activities that are likely to be carried out by caregivers, namely: housekeeping, personal hygiene, meal preparation, medical care, transportation, financial and legal assistance, including spiritual and emotional support for the patient's benefit.

Women are viewed as typical caregivers; as a result they are faced with multiple tasks and responsibilities (Eneh, 2010). Many of them are deemed to benefit from interventional support service programmes such as talking about their challenges to their significant others and from effective public health services to preserve own health and that of HIV/AIDS patients (Eneh, 2010). Gahagan et al. (2004) found that many caregivers claimed that emotional support in the form of empathy, appreciation and commiseration was an essential element of supportive relationships for themselves.

Self-care and the support from family, friends and the community are regarded as key elements of care for the caregiver. However, caregivers are thought to fear that the support they receive from other people would not be of the kind they wanted. As caregivers, soliciting help often entailed submitting to intrusions that they did not consider appropriate. For example, people from the community enquiring about the condition of a member who is known to be ill and living in the hospice (Gahagan et al., 2004).

Significantly, contemporary assessments from lay caregivers (and family members) are often reported as being closer to patient assessments than those of staff (Higginson & Gao, 2008).

Caregivers' Challenges

Van Dyk (2012) argues that many caregivers are afraid that they may become infected with HIV and lack of knowledge about the disease, treatment, emergency situations and community resources often hamper Home and Community-Based Care. Stressors that are unique to HIV/AIDS caregiving include fear for infection through occupational exposure to death and dying patients (Moremi, 2012).

In the United States of America (USA), Gahagan et al. (2004) argue that caregiving has an impact on the health, work and leisure, and the need for adequate transportation and finances in the caregivers' and the recipients' lives. This has been noted as most hospices are

non-governmental organisations, and they have to generate money to create own funding.

To some extent, the social lives of caregivers go through severe changes due to the tremendous additional workload of providing care. Naidu (2005) suggests that caring for people with a terminal disease is a physically, emotionally and sometimes spiritually exhausting, that places a great deal of pressure on the coping resources of the caregiver.

Another challenge is the physical health of caregivers which is impacted by such factors as having to often physically lift and change the patients, which could affect the physical health of the caregivers. Caregivers frequently identified exhaustion and loss of stamina and strength related to provision of care (Gahagan et al., 2004). In addition, caregiving sometimes results in physical injury to the caregiver due to the large amount of heavy lifting.

Hughes (2008) states that research has documented a decline in caregivers' health as they perceive themselves as burdened. Caregivers are prone to increased health-risk behaviours such as: smoking, higher use of prescription drugs, fatigue and sleep disturbances, lower immune functioning, altered response to influenza shots, slower wound healing, increased insulin levels and blood pressure, altered lipid profiles and higher risks for cardiovascular diseases (Reinhard et al., 2008). Burton, Newsom, Schulz and German (1997) found that the chances of caregivers not getting sufficient rest nor having time to exercise and recuperation time from illness were high.

The Role of Hospice

In the case of home-based-care institutions, the idea of hospice emanated from the impact of HIV/AIDS on the health care system to provide an alternative to institutionalised health care (Fox et al., 2002). The World Health Organisation (2002) highlights that in the USA and African countries, formal and informal caregivers provide the health services in order to: promote, restore and maintain the person's maximal level of comfort, function,

health and care towards a dignified death.

Fox et al. (2002) saw the need for a comprehensive integrated approach that addresses the: medical, psychosocial, spiritual and emotional needs in less developed countries with minimal resources and health budgets. According to McCall, Driver, Bauer, and Knickman (1997) various types of hospital providers include free-standing hospitals, home-care agency-based hospices, hospital-based hospices, and skilled nursing facility hospice care.

The Ecological Perspective

The ecological perspective is well-suited to qualitative research (Dey & Hurtado, 1995) because the developmental branch of psychology is concerned with how people's behaviour and experiences are related to their everyday environment, the first step to be considered is to study opportunities and constraints in their environment; particularly people's perceptions of them and qualitative research prioritises individuals' unique experiences (MacLaren & Hawe, 2005). Bronfenbrenner (1979) suggests that interactions with others and the environment are crucial to development. He contends that individuals all experience more than one type of environment. For example, the microsystem (the immediate environment in which a person is operating), the mesosystem (the interaction of two microsystem), the macrosystem (the cultural context), the exosystem (the environment in which an individual is not directly involved), and the chronosystem (events occurring in the context of passing time).

Bronfenbrenner's (1994) ecological theory of development is best suited for this study's theoretical framework for its conceptualisation of the interactions between individuals and their environment. The participants of this study were viewed as individuals who have their own origins such as families and loved ones. Therefore, working at the hospice makes them part of the system with sub-systems. For example, they follow the hierarchy relevant to their job description which entails: the co-ordinator, managers, staff and patients. As such

they may not avoid being influenced by the environment and the external environment such as the country's health system or government. There is therefore interrelatedness amongst members of the hospice and their different environments or contexts: microsystem, mesosystem, macrosystem, exosystem and chronosystem. The resilience perspective suggests that systems and system parts cannot be understood and analysed in isolation from the bigger picture (Rankin, 2013).
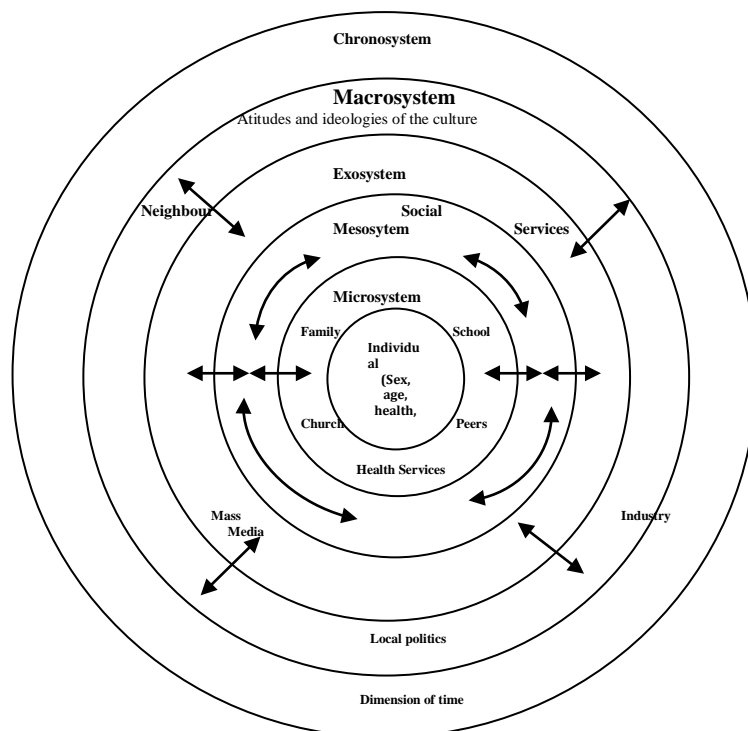
Figure 1: Bronfenbrenner's Ecological Theory of Development (MacLaren & Hawe, 2005, p. 10)

The ecological perspective is viewed, according to Waller (2001) as a way of thinking and organising knowledge that emphasises interrelatedness and interdependency. This perspective provides a good context to understand concepts of risk and resilience. This perspective concurs with human ecology theory regarding the fact that human development is influenced by mutually progressive accommodation between growing organisms and their environment.

A combination of the ecological and developmental perspectives should be employed to view the family as an open system that functions in relation to its broader socio-cultural context and evolves over the multi-generational life cycle (Carter & McGoldrick, 1999; Falicov, 1995). This approach is guided by a bio-psycho-social systems orientation, seeing problems and their solutions in view of multiple recursive influences involving individuals, families, and larger social systems (Walsh, 2002).

According to Campbell, Nair and Maimane (2005), the ecological perspective, also known as the social ecological model, is a methodological framework used to determine dynamic relationships between individuals and includes multiple level perspectives of the social environment. It is Cutting's (1982) view that an ecological perspective sees the proper unit of analysis as the organism in its natural environment and it indicates that within ecosystems all organisms are interrelated (Campbell et al. 2005).

Each of these systems as postulated by Bronfenbrenner (1979) is characterised by: roles, norms or expected behaviour and relationships. For example, an individual in most cases acts within his or her own family or significant others. Similarly, Chen (2012) claims that microsystems focus on patterns of activities, social roles and interpersonal interactions experienced by individuals within their immediate environment.

The ecological perspective's focus is precisely on the individuals and their environment or influences which promote resilience. Resilience is viewed by leading theorists who are inclined to the ecological perspective as a relational process that manifests itself and is observable in a system and over time (Hawley & De Haan, 1996; McCubbin & McCubbin, 1996; Walsh, 1996). According to Cohler (1987) interplay of processes within the individual is key; to any system as well as its social context contribute to resilience (Greeff & Holtzkamp, 2007).

Resilience signifies a shift from a focus on individual pathology to an understanding of, and studies on, how human beings react to adversity and overcome obstacles (Anthony, 1987; Cohler, 1987; Hawley & De Haan, 1996). This shift relates to a focus on strengths as opposed to a focus on pathology or deficits (Walsh, 2003).

Models of Stress

De Haan, Hawley and Deal (2002) are significant researchers of the roller-coaster model of Hill (1958) in which a stressor event precipitates several stages that an individual can encounter i.e.

- A period of disorganisation which may be marked by increased conflicts, a search for effective ways of coping, and a general atmosphere of confusion, anger, and resentment.
- A period of recovery during which an individual discovers new means of adjusting to the crisis, and
- A period of reorganisation in which an individual reconstructs him/herself at above or below his/her pre-crisis level of functioning.

Antonovsky (1979) developed the salutogenic model (1979), arguing that stressors are omnipresent in human existence. Moremi (2012) describes this model as the process of staying healthy despite exposure to stress. Resilience signifies a shift from a focus on pathology to an understanding of studies on how human beings react to adversity and overcome obstacles (Anthony, 1987; Cohler, 1987; Hawley & De Haan, 1996).

Salutogenesis for Antonovsky (1987) focuses on the strengths and successful coping with life stressors rather than focusing on ill-health and poor well-being that result from stress. The salutogenic model came to be known as a sense of coherence model derived from a theoretical analysis of what a large variety of generalised resistance resources seem to have in common and that might explain how they work (Antonovsky & Sourani, 1988). McCubbin, Patterson, and Glynn (1996) developed the sense of coherence model and they

contend that regenerative power, reorganisation after a period of crisis, and adaptation became central concepts as well.

McCubbin and McCubbin (1993) state that resilience is a shift aimed at contributing to treatment and proactive interventions for humans at risk through a provision of what Walsh (1996) describes as psychosocial inoculation. However, despite the need for community volunteers to provide psychosocial support, they often find it hard to fulfil their supportive role based on their feeling that they had not been adequately trained to handle the emotional challenges of vulnerable communities (Ungar, 2012).

Loots et al. (2012) claim that for most community volunteers, this can be a frustrating experience, as they are aware of the fact that vulnerable communities need their support, yet they do not know how to support individuals in a way that may be fulfilling for both the vulnerable individual and community volunteer. Consequently, there is a need for ongoing research on the way that volunteers may support vulnerable individuals, which can inform practice (Lehman & Sanders, 2007).

One of the main challenges that affect community volunteers in supporting vulnerable people is that they are often of the opinion that they have not been equipped with the skills necessary to support people, especially regarding emotional difficulties (Akintola, 2010). In addition, culturally, it is not always easy for caregivers to talk to other people about their emotional challenges. For example, in some African cultures it is taboo to talk about death during childhood (Ebersőhn, Ferreira & Loots, 2008).

The presence of negative experiences is vital for the development of resilience (Rutter, 1999). Wolin and Wolin (1993) indicate that resilience is a rebound from negative experiences in early life. McCubbin and McCubbin (1996) introduced a resiliency model which rests heavily upon the presence of crisis and vulnerability and numerous stressors. The

presence of crisis and vulnerability highlight the processes that signify a person as resilient with outcomes that are satisfactory when confronted by stressors.

According to McCleland, Atkinson, Clark and Lowell (1958), volunteering and specifically caregiving, is demanding, implying responsibilities that cannot be avoided, nor delegated to people who are not interested in caring for others. A range of emotional challenges have been impacting South African communities, affecting and emphasising the need for emotional and psychological support to vulnerable communities (Bezuidenhout, 2003).

Conclusion

This chapter focused on presenting a literature review which provides the background of the current study. The chapter also discussed Bronfenbrenner's ecological perspective as the key theoretical framework of the current study. The next chapter will comprehensively discuss the research method employed for this particular study.

CHAPTER 3

RESEARCH METHODOLOGY

Introduction

This chapter focused on the research design where the following were discussed: research aims, the sample of participants, data collection and data analysis using thematic analysis as well as the ethical considerations of the current study.

Aims of the Study

The main aim of the study was to explore how the hospice's caregivers perceive themselves as working with the terminally ill patients, especially those infected with HIV/AIDS. This study sought to expand on the stories of the employees of a South African hospice and to ascertain how they feel and cope when working with terminally ill people. The researcher aimed to establish the nature of interventions provided for caregivers at their workplace and whether those interventions cater for their needs. A platform was created to allow the caregivers to have a voice regarding their issues of concern.

Field of Knowledge

Epistemology of Social Constructionism

Social constructionism is viewed by Visser and Moleko (2012) as a central metaphor that is used and understood in widely divergent and conflicting ways by different thinkers. Gergen (2008) defines social constructionism as an account of knowledge generating practices both scientific and otherwise. It traces the origin of knowledge, meaning or understanding to human relationships. This phenomenon was utilised as a platform to be both realist and social constructionist as these ways of thinking are compatible with each other (Visser & Moleko, 2012).

The researcher considered using this approach because, as stated by Denzin and Lincoln (2002), social constructionism addresses questions that focus upon evaluative,

political, and pragmatic concerns pertaining to choices a person makes. Macnamee and Gergen (1992) explain that individuals, in their processes of constructing the world, are bound by the beliefs, maps, and premises that they have regarding the world. This is a paradigm that rejects objectivity and the idea that one can separate the study of an object from the study of the knowing subject (Macnamee & Gergen, 1992).

The main purpose of social constructionism is one of a continuously unfolding conversation between the interviewer and participant about the nature of knowledge and our understanding of the world (Cunliffe, 2008). Social constructionism involves the creation of an open field of possibility which for most social constructionists means that all voices may justifiably contribute to the dialogues on which our future depends. It invites a posture of infinite curiosity where the caregivers can be in a position to be listened to as experts of their own experience (Gergen & Gergen, 2012).

Research Design

The researcher chose qualitative methodology as a way of eliciting participant accounts of meaning, experience or perceptions (Mouton, 2001). The study intended to capture what participants say and do as a product of how they interpret the complexity of their world, and more specifically to understand their viewpoints (Burns, 2000).

A qualitative research design was also chosen as it seeks to understand the meaning participants attach to their personal experiences. It implies the entire process of research from conceptualising a problem to writing the narrative (Creswell, 1998). This research design allowed the goals of the study to be achieved as noted by Padgett (1998). As suggested by Lincoln and Guba (1985) trustworthiness was achieved, namely a study that represents as closely as possible the perspectives of the research participants. In essence, trustworthiness ensures reliability and validity of qualitative data. Four concepts that work together to

achieve trustworthiness will later be discussed in detail, namely: credibility, transferability, dependability and confirmability were used (Lietz & Zayas, 2010).

Amongst other reasons in utilising qualitative methods is that a qualitative approach allowed the researcher to study selected issues in depth, openness, and detail as they identify and attempt to understand the categories of information that emerge from the data (Terre Blanche, Durrheim & Painter, 2006).

This study examined the experiences of caregivers at the Gauteng-based hospice with patients living with HIV/AIDS by entering the participants' life world. In addition, it was pivotal to put oneself in the participants' shoes as well as analysing the conversations and interacting with them in a naturalistic manner (De Vos, Strydom, Fouché & Delport, 2005). The goal of this research method was to study the caregivers' experiences from their perspective, to describe and understand rather than explaining and predicting their behaviour (Babbie & Mouton, 2010). Similarly, De la Rey and McKay (2006) contends that qualitative research is concerned primarily with human understanding.

Research Participants

The target research participants in this study were a Gauteng-based hospice's employees with a nursing background. The participants had to meet the following requirements: their ages had to be between 30 and 70 with at least a Grade 12 level of education.

Non-probability sampling was utilised because the odds of selecting a particular individual were not known since the population size of caregivers was not fixed (De Vos et al., 2005). Under this type of sampling the researcher focused on purposive sampling which is based on the sound judgment of the researcher in that a sample is composed of elements that contain the most characteristic, representative or typical attributes of the population (De Vos et al., 2005). The researcher opted to use purposive sampling because it enabled access

to the participants in the study. Most importantly, the main purpose of purposive sampling was to focus on particular characteristics of the hospice population of caregivers that were of interest, namely those which best enabled the researcher to answer the research question. That is, to what extent are caregivers who look after HIV/AIDS patients at this Gauteng-based hospice resilient?

The hospice is a multi-cultural organisation, accommodating 20 homeless people who are diagnosed as terminally ill. However, it still caters for terminally ill patients who have families but without caregivers. The aim of the hospice is to assist patients to thrive for a period of about three months and also to assist them towards independent living and a re-integration into society. Through the support of strong partners such as United States Agency for International Development the hospice was able to develop a holistic HIV/AIDS programme including: awareness raising, prevention, residential and home-based care.

The participants were required to be able to express their feelings and thoughts in the language that best suited them. For example, all participants could choose to communicate in Sepedi, IsiZulu or English which were the languages used in the interviews as the researcher could converse in the above-mentioned languages. Although the interviews were conducted in Sepedi and isiZulu they were later translated into English transcripts.

Data Collection Method

Semi-Structured Interview

Semi-structured interviews were used to collect the data in the current study. This data collection method enabled the researcher to tap into a specific area of knowledge while still allowing considerable flexibility in scope and in depth (De Vos et al., 2005). Interviews were used in order to gain a detailed picture of participants' beliefs about, or perceptions or accounts of their care-giving experience. The researcher was able to follow up avenues of particular interest that emerged in the interview and therefore participants were able to give a

fuller picture. Semi-structured interviews are suitable in terms of complexity or process, or where issues were controversial or highly personal to individuals.

The researcher had a set of predetermined questions in terms of an interview schedule, but the interview was guided by the schedule rather than be dictated by it (De Vos et al., 2005). After the participants were made to feel at ease it was essential to facilitate and guide the participants instead of dictating their encounter. In the interviews, this flexibility allowed the participants to introduce issues the researcher had not thought of. In this relationship, the participants were perceived as the experts on the research subject and were therefore allowed maximum opportunity to tell their stories. To generate a rich description the questions asked were formulated to be open-ended (De Vos et al., 2005).

Taking into consideration that semi-structured interviews generally last for a considerable amount of time and that they could become intense and involved the time scheduled was approximately 60 minutes.

Data Gathering Procedure

As a way of gaining entry at the hospice, a written request was first made to the relevant gatekeepers, i.e., the centre manager and her assistant to assist in accessing potential participants. A meeting with the prospective participants was arranged to inform them about the rationale of the study. The meeting aimed at obtaining permission and the consent of the participants as partakers in the research. Furthermore, this was an opportunity that allowed the researcher to join with the participants.

The interviews took place in one of the spare offices of the hospice. They were held on a one-to-one basis. The interviews were audio-recorded to ensure authenticity of the voices of the participants. All the voice recordings were then sent to a professional translator in order to be translated and transcribed into English.

Trustworthiness of Data

The key principle of good qualitative research as noted by Lincoln and Guba (1985) is found in the notion of trustworthiness. According to Babbie and Mouton (2010), trustworthiness refers to how the inquirer can persuade the audience that the findings of a study are worthwhile.

Seale (2002) argues that trustworthiness is always negotiable and open-ended. In the same way, Marshall and Rossman (1995) observe that all research must respond to principles that stand as criteria against which the trustworthiness of the project can be evaluated. For a good qualitative interpretive analysis, the following constructs are necessary: credibility, transferability, dependability and confirmability.

Credibility

The goal of the research was to demonstrate that the inquiry was conducted in a manner that ensured that the participants were accurately identified and described (De Vos et al., 2005). Credibility was achieved as the participants were identified according to: gender, age, and education which also ensured transparency. The research area, namely the hospice which the researcher investigated, was visited on four occasions. In striving for credibility, the researcher continually reflected on her subjectivity and biases. The researcher also engaged extensively with the participants with the aim of building a trusting relationship which implied professional integrity, intellectual, methodical capability and intellectual rigour (Lincoln & Guba, 1985). Babbie and Mouton (2010) maintain that prolonged engagement allows the researcher to gain an in-depth understanding.

Transferability

Shenton (2004) suggests that transferability is concerned with the extent to which the findings of one study can be applied to other situations. Saturation was achieved in terms of

this particular context. However, beyond this context saturation is unlikely to be achieved as other hospices' caregivers may report different experiences of caregiving. Therefore it is recommended that similar studies be conducted in future. Lincoln and Guba (1985) showed that the researcher can refer back to the original theoretical framework to show how data collection and analysis will be guided by concepts and models (De Vos et al., 2005). The researcher compiled an audit trail of transcripts and her journal of her self-reflexivity which are locked away safely, and can be requested by other researchers. The researcher observed the importance of documenting research material upon request by a potential researcher who might be interested in a similar study. Multiple informants were used to strengthen the study's usefulness. For example, six participants were identified for this current study.

Dependability

Dependability is based on the notion that if the inquiry were to be repeated with the same or similar respondents in the same context, its findings were likely to be similar (Shenton, 2004). In addition, the researcher ensured that the processes that unfolded within the study were reported comprehensively, accurately and cautiously by going through each transcript and discussing main themes with supervisors.

Confirmability

Confirmability captures the traditional concept of objectivity (De Vos et al., 2005). The findings of research are the product of the focus of the inquiry and not of the biases of the researcher (Babbie & Mouton, 2010). It was crucial to determine if the conclusions, interpretations, and recommendations can be traced to their sources and if they were supported by the inquiry. In striving for confirmability, the researcher constantly reflected on her research by means of journal entries.

Authenticity within research indicates whether or not the description and relevant explanations correlate with each other. It implies the degree to which different points of view are fairly and equally represented by the researcher (Denzin & Lincoln, 2002; Spencer, Ritchie, Lewis & Dillon, 2003). Therefore the researcher strove for authenticity by reporting contradictions and conflicting values that she found in her study (Huberman & Miles 2002). Furthermore, a literature review of crucial theoretical constructs was performed to describe and confirm the relevance of research by other researchers.

Ethical Considerations

Ethical issues are deemed significant when conflict arises between the values of the community in matters such as freedom and privacy as well as when the researcher chooses one form of conduct and respects one moral principle but transgresses another (De Vos et al., 2005). The Health Professions Council of South Africa (HPCSA) recognises the importance of maintaining confidentiality when working with people. According to the Health Professions Act 56 (1974) the participants' privacy and confidentiality needed to be guaranteed and safeguarded in order to create a safe space and to allow them speak openly about issues of concern. That is, participants at the Gauteng-based hospice were informed that the discussions of the study would be used for research purposes and that their names would not be mentioned in the research study and any subsequent publications. Participants were informed that only anonymous findings would be published and extracts with identifying information removed.

Permission in the form of a signed letter from the hospice to conduct the study was obtained before conducting the study. It was stated in the letter that feedback regarding the study's outcomes would be made available to all those interested. Participants were informed in writing that the research was part of the researcher's Master's degree requirement. Prior to

the interviews, a signed written informed consent of the participants for the interviews and recordings was obtained (Terre Blanche & Durrheim, 2002).

Terre Blanche and Durrheim (2002) state that informed consent has often been seen as the only determinant of ethicality in research. However, specifically the standard components of consent, usually given in writing are provision of appropriate information, voluntary participation, freedom to decline or withdraw after the study has started and formalisation of the consent. Participants are also expected to be competent and capable of understanding the research. This meant that as it was necessary for the researcher to provide potential participants with clear, detailed, and factual written information about the study, its methods, its risks and benefits, along with assurances of the voluntary nature of participation, and the freedom to refuse or withdraw without penalties.

The participants were reminded that their participation in the study was voluntary and that they could withdraw from participating in the study at any time. No one was forced to participate (Babbie & Mouton, 2010). It was emphasised that in responding to the questions, participants could choose to answer what resonated with them and refuse to answer any question to that could make them uncomfortable and this would not have any implications on their employment or lifestyle. They were alerted that there could be emotions evoked during the process of gathering data and in such instances debriefing contact details would be provided for debriefing options for the participants.

A meeting with the six prospective participants was arranged to inform them about the rationale of the study. The meeting aimed at obtaining the consent of the participants as partakers of the research. All volunteering participants in the study were granted assurance to remain anonymous in that, while their words would be made known, their identities would remain confidential. All prospective participants consented to be interviewed.

Self-Reflexivity

It is fundamental to embark on a process of reflexivity when conducting a qualitative study, especially one that is of a sensitive nature. Reflexivity according to Strydom (2005) is the ability to formulate an integrated understanding of one's own cognitive world, especially understanding one's influence or role in a set of human relations. Furthermore, self-reflexivity is a quality of metacognition, thinking about one's perceptions and ideas.

My challenge in selecting the research topic was whether or not it would interest me or catch my attention. My interest to pursue this research study was influenced by the fact that it was part of my community psychology project during my Master's in Clinical Psychology training and the issues related to HIV/AIDS and as I have closely witnessed people suffering from this disease. It was comforting to carry out a task that I felt connected to.

Furthermore, in my personal opinion, serving other people can be perceived as a way of being and also symbolises humanness. As an African female, this was to my advantage when conducting this study because all participants were African adults who mostly appeared relaxed and openly discussed sensitive issues with me and I could converse easily in the participants' choice of language.

Ramose (1999) claims that Ubuntu is the root and the basis of African philosophy. I became conscious of the fact that being human is not enough, but it is about the respect or humanity you show and give unto others. This links well with Grills (2006, p. 49) definition of self that "I am because we are, and since we are therefore I am." Grills (2006) also showed that self in relation to others is the focus of individual experience.

However, my venture into the hospice put me in an ambiguous state as to whether my focus should be on research or to also utilise my tools as a therapist. I realised that separating the two is not always possible because such skills as negotiating entry were pivotal.

Establishing rapport could not be put aside as that could have an impact on how the caregivers interacted with me. I joined with the interview participants and co-created space for safety by conversing with them about general matters rather than immediately interviewing them.

I also became aware that one cannot not feel the impact or avoid impacting others. The manner in which I connected with participants varied as they were diverse individuals. For example, most of the caregivers presented in a friendly and co-operative manner. However, others' affect was blunt. Some caregivers responded briefly to questions and therefore I found myself probing to a greater extent, whereas the others were forthcoming and gave comprehensive details. In reflection, the behaviour of participants varied in that some seemed affected and overwhelmed, while the others presented in a detached manner.

My first visit for negotiating entry at the hospice raised questions as to whether access would be offered or not. After I was granted permission by the head of the institution I felt a sense of relief.

My experience of interviewing the participants was that I came across key extracts that were of significance because of the richness of the participants' explanation of their job experience as individuals and collectively as well as attaching the meaning of being a carer to their personal experiences. I found the following extracts standing out for me in terms of how the participants were taking care of patients: "We take care of patients the same way. I try to explain to those who are not HIV positive that it can happen to anyone. I try to make sure they understand each other and do not discriminate against one another (Kholofelo). This extract stood out for me because Kholofelo treats patients equally with the same warmth and compassion irrespective of the nature of their disease. Puleng: "There is no difference especially with regards to our patients. After all they are the same as they all take treatment and I treat them the same. What I like is that sometimes some of them come back to tell us

that they are well as they have been taking their medication." Sipho further stated: "In actual fact I think the patients see a difference in themselves. If I walk into a ward and see a patient, I take him or her as a human being. That is, I do what I am supposed to do. But I think patients themselves are the ones who give themselves a stigma before someone else can do that." It is evident from Sipho's comments that some patients, because of their awareness of the disease, for example, HIV/AIDS, they carry the burden because of the societal stigma associated with their disease which might be the cause for them looking down on themselves.

Joining with the participants by showing empathy and containing them was crucial, especially when they spoke about sensitive issues. The interview questions were asked from a not-knowing position to understand meanings as created and experienced by individuals in conversation with one another (Macnamee & Gergen, 1992). Lock and Strong (2010) also claim that human action takes place in a reality of understanding that is created through social construction and dialogue. I was an active listener and reflected in order to gather information. My involvement with the participants was an inspiration for me in their dedication to their work and the manner in which they cope in difficult situations.

Setting the Context

The researcher chose the hospice based on the notion that it is a multi-cultural organisation, accommodating twenty homeless people who are diagnosed as terminally ill. However, it also caters for terminally ill patients who have families but without caretakers. The hospice aims at assisting the patients to thrive for a period of about three months and also assists them towards independent living and a re-integration into society. In 2011, the organisation started operating a mobile clinic to provide basic, accessible health care to the community. Home-based care was extended to older and mentally ill people.

As such the hospice renders the following services: HIV/AIDS awareness programmes, education and prevention, provision of holistic HIV/AIDS palliative care and

support, voluntary counselling and testing, care for orphans and vulnerable children, building institutional capacity of partners, basic health and social services for older people, psychosocial and residential care for people with mental illness and access to basic health care services through a mobile clinic.

Selection of Participants

Although the hospice had other staff members such as a social worker, pastor and general workers such as cleaners and gardeners, six people were interviewed who specifically worked as caregivers and pseudonyms were used to refer to participants. Kholofelo is a black single female in her thirties who speaks Sepedi and resides in Pretoria with her children. She has a nursing diploma, and has been working for the hospice as a caregiver for four years. She presented as well-groomed and was calm in her manner during our conversation.

Kholofelo explained that on arrival at work at 7am, her duties entailed bed-bathing, changing patients' diapers, dressing their wounds and feeding them. Furthermore, Kholofelo escorts residents to the clinic or hospital for their doctor's appointments. There is a daily programme that focuses on providing health talk to educate patients on their illness and to comply with treatment. She emphasised that in the hospice team members also render spiritual services to encourage them.

Tirisano is a black female in her forties. She is married with children and has been together with her husband for twenty years. Her home language is Sepedi. Tirisano has a certificate in auxiliary nursing, has been employed by the hospice as a caregiver for two years. She outlined that the daily programme at the hospice involved her focusing on bed-bathing patients, wound dressing, bed-making, health talks, provision of medication and facilitating physical exercises to patients.

Puleng is a Sepedi-speaking, black female in her sixties. She is living with her partner of nearly four decades, her children and extended family members. She has a high school

education, and thirty-five years of auxiliary nursing experience, and has been employed by the hospice as a caregiver for five years. Puleng stated that in the morning when she arrives at work she obtains patients' report from the night duty colleagues, baths patients and dresses them, changes their adult underwear, feeds the helpless patients, hold devotions every day at 11 am, for an hour to uplift their spirits.

Tumelo is a Sepedi-speaking black female in her early seventies. She is divorced, has children and currently stays with her grandchildren. She has a degree in nursing. She has over fifty years in the nursing profession and a few months in the hospice (she is the nursing sister in charge) as a supervisor for the caregivers. She outlined that her duties entailed supervising caregivers who do nursing care or care-giving, drafting of duties, taking care of the patients, and teaching the nursing students.

Sonto is a black female in her early thirties. She is married with children and has been together with her partner for twelve years. Her home language is Ndebele and also conversant in isiZulu. She has a nursing diploma and has been employed by the hospice for two years as a centre manager. Her duties involve supervising the caregivers, kitchen staff and the gardener. She helps the caregivers with offering total patient care.

In contrast, Sipho is a black male in his mid-thirties. He is single and has no children. His home language is Ndebele and also conversant in isiZulu, his highest education is a diploma in business management and has been employed by the hospice for eight years. His job as a caregiver entails bathing patients, dressing them and their wounds. Sipho describes his day as starting with devotions where patients and team-members pray and have a spiritual lesson to encourage patients. The health talks educate patients to take care of themselves and about their symptoms or illness. In summary, the participants are five females and one male, all Africans. Their ages range between 30 and 70, their highest level of education is between Grade 12 and a Bachelor's degree and most of them have a nursing background.

Data Analysis Method

The goal of qualitative data analysis to transform data into findings. Babbie (2001, p. 10) defines data analysis as "a process of making sense of what has been observed". According to De Vos et al. (2005), data analysis is a process of bringing order, structure and meaning to the mass of collected data. The researcher used a tape recorder and field notes to record the interviews. The responses of the participants were transcribed in separate notebooks for each interview and notes were taken.

After conducting the interviews, data collected from each interview was analysed and verbatim records of the interviews were transcribed in order to preserve the information. In terms of managing or organising data, a data inventory system was developed, correlating the field notes and transcripts. In addition, field notes on important aspects were recorded by the researcher and were used for further probing.

In the present study, the data obtained was subjected to thematic analysis which offers an accessible and theoretically-flexible approach in analysing qualitative data and its richness in detail when organising and describing data (Braun & Clarke, 2006). After transcribing the interviews, the researcher read the texts several times in order to gain insight into the respondents' answers. The researcher identified the main themes in how the caregivers perceive themselves in working for a hospice, which subsequently lead to detailed sub-themes: following these patterns and larger categories being identified and outlined. That is, the data analysis of this study compared segments of data between each of the interview transcripts which helped to identify similar and different points of view within a particular category and aided in generating further concepts and subcategories (Neuman, 1997).

The researcher assigned colour highlights to segments and similar segments had the same colour and different segments had an alternative colour to make the analysis easier.

Subsequently, it was necessary to analyse data by extracting themes. The process involved the researcher highlighting each theme using a different colour to differentiate themes.

The inductive approach in analysing data ensured that the themes identified were strongly linked to the data. The coding schemes for the identified themes and sub-themes were applied. The usefulness and centrality of the data presented in the themes and sub-themes were also evaluated.

In terms of searching for alternative explanations, the researcher utilised her critical analytical competence to identify and document alternative explanations, thereby justifying any apparent plausible explanation.

Conclusion

This chapter offered an account of the research method employed in this research study. The fundamental steps followed by the researcher in the qualitative data analysis were described, namely: the procedure, research method, data collection method (semi-structured interviews), and data analysis using thematic analysis. Cautious consideration of ethics was applied as the study involved the sensitive research area of HIV/AIDS. The next chapter presents the findings and discussion of the present study.

CHAPTER 4

FINDINGS AND DISCUSSION

Introduction

The current chapter discusses the findings of the study. To substantiate the findings, extracts from the caregivers' responses were quoted verbatim. In terms of the data collected the findings were presented in accordance with the stressors of caregiving at the hospice and in terms of the strategies employed to cope with those stressors. Issues of emotionality regarding the caregivers' experiences were elaborated on. Furthermore, this chapter discussed the comparison of the findings of the current study to previous studies in the field considering the theoretical contributions outlined in the literature review chapter. It is important to note that the content of the themes overlap and therefore they will be presented as such.

Demographics of the Participants

In order to maintain anonymity, pseudonyms were used to refer to participants. There were five females and one male who volunteered to participate with their ages ranging from 30 to 70. Most participants were trained as either auxiliary or professional nurses prior to being employed as hospice caregivers.

Below is the table with the details of the participants.

Participant	Age	Home language	Marital status	Years of work experience
Kholofelo	Thirties	Sepedi	Single	Less than 5 yrs
Tirisano	Forties	Sepedi	Married	Less than 5 yrs
Puleng	Sixties	Sepedi	Married	30+ yrs
Tumelo	Seventies	Sepedi	Divorced	Over 50 yrs
Sonto	Thirties	IsiZulu	Married	Less than 5 years
Sipho	Thirties	IsiZulu	Single	5 to 10 yrs

Table 1: Summary of demographic profile of participants.

All participants resided in Pretoria, South Africa.

Research Context and Personal Observations

The hospice is under a leadership foundation that offers health support in the city through various outreach and drop-in centre programmes, assisting people in need through referrals to hospitals, long-term facilities and health education. The foundation started to address HIV/AIDS in the inner city in a multi-organisational partnership. Through the support of strong partners such as USAID they were able to develop a holistic HIV/AIDS programme including awareness raising, prevention, residential and home-based care. The leadership foundation currently manages the hospice, a multi-cultural organisation, accommodating twenty homeless people who are diagnosed as terminally ill.

I made observations at the hospice over a period of one year as it formed part of my Master's degree community project. The hospice is located in a quiet cul-de-sac. Entering the premises gave me a feeling of warmth and homeliness. The hospice is a renovated house converted into wards. There are extra rooms that are used by the caregivers for their daily health talks with patients, spiritual devotions, and to accommodate visitors. The patients also

have access to television in a common dining area. The caregivers prepare meals in a spacious kitchen. The hospice has a large vegetable garden which supplies the vegetables that are used to prepare the patients' meals. Next door to the hospice is a halfway house for the patients diagnosed with mental disorders. The two houses are accessible. Therefore patients have the opportunity to interact with one another by sitting outside under the trees.

The hospice consists of six permanent caregivers and student nurses who come on occasionally for their practicals. At any given time there will be caregivers on night duty. When I was present at the hospice, I observed that the interaction between the patients and caregivers appeared warm and cordial. The caregivers were taking turns to attend to the patients who were bed-ridden and they followed the roster. The patients with mobility adhered to the daily programme such as attending devotions where they sang and prayed. Some of the patients participated actively during the health talk discussions which focused on empowering the patients with basic health skills.

Themes

The findings obtained from the interviews are presented under the following categories:

Category	Themes	Sub-themes
Individual resilience resources	• Personal experiences of the job: Difficulty in adjusting to work and personal loss	 Protective and recovery factors Loss Strength Shock Disconnectedness Responsibility Problem-solving skills Ability to empathise with others

		Ability to adapt to change
	Significance of length of service	Work experience Assertiveness Depression Stress Trauma
	Social Support	Voice not heard
	Recognition and Rewarding of caregivers	Positive outlook on life
Organisational resilience resources	• Definitions of roles:	
	Seeking clarity of roles and responsibility	Obsolete Pragmatics Over-involvement Sense of understanding
	• Job fulfillment	Fulfillment Passion
	• Fear for infections	Prevention Fear
	• Coping strategies:	
	Dealing with occupational stress	Social regulatory abilites Communication Ventilation Stress

	Employee Support	Positive frame of mind
	• Emotions and feelings experienced by caregivers; Negativity/feelings of disconnection Feelings of helplessness Feelings of anger and frustration Feelings of disappointment	Respect
Relationship resilience resources	Ecological resources: Familial resources	Support from home
Community resilience resources	• Access to resources: Insufficient funding Inadequate - remuneration	Lack of resources De-motivation Passion Sadness Salary not paid on time Lack of benefits

	Access to training	Limited potential for academic advancement
Cultural resilience resources	Spirituality	Faith Prayer is strength Religion Hope Sense of meaning

Table 2: Themes and sub-themes.

Analysis of Themes

The concept resilience provided the lens for the findings of the current study as employed by the International Resilience Project (2006) under the premise that resilience is both the individual's capacity to navigate to health resources and a condition of the individual's family, community and culture to provide these resources to culturally meaningful ways. Additionally, this section focused on the four significant and ecologically nested aspects of each individual's life related to resilience namely: individual, relationship, community and cultural factors (IRP, 2006). Organisational resilience resources borrowed from the study conducted by Graaf (2011) was discussed below. The following themes were drawn from the data provided by the caregivers:

Individual Resilience Resources

    Personal Experiences of the Job

Although the participants work in the same organisation, they had their own unique experiences. They have different worldviews and their realities were often not the same. Despite engaging in some duties collectively, sometimes they individuate or differentiate. Their experiences resonate well with McAdams's (2006) view that people narrate personal events in different ways for different listeners. McAdams (2006) argues that a person's internalised evolving story of the self or narrative identity constitutes a distinct layer of personality itself.

Graaf (2011) elucidates that experience has been viewed as possible mediating factor of the stresses of working with traumatised people. She further argues that the findings of some studies claim that experience is a protective factor against stress or burnout and explicit traumatisation. Lin, Fee and Wu (2011) emphasise that caregivers typically experience both negative and positive feelings simultaneously.

    Difficulty in Adjusting to Work and Personal Loss

In view of literature reviewed previously, Vitaliano, Zhang and Scanlan (1991) experienced caregivers to be extremely stressed at the beginning of the caregiver experience and adapt as time progresses. Most participants of the Gauteng-based hospice reported that their first encounter of working with patients was difficult because most patients do not live long due to being terminally ill. The caregivers have shared how initially they were shocked during their first encounter of working with terminally ill patients. They explained that the nature of their job required them to numb themselves or become selfless. Kholofelo stated:

> It was not easy to work here at first but you get used to it. You see a person every day when he/she passes on is like you are losing part of your life. You feel you did not do hard enough; you become emotional but try hard to stay strong and not show your emotions.

Studies cite that protective and recovery factors are regarded as the dual functional nature of resilience. They are deemed to facilitate adjustment or the ability to maintain integrity and functioning, and to fulfil developmental tasks (Black & Lobo, 2008). Puleng revealed how her role as a caregiver does not exclude her from being empathic and yet it requires her to be a responsible human being. She relayed how her experience at the hospice gave her a sense of awareness of the poverty background of some patients. She demonstrated this by saying:

> My experience in working with people who are dying is that most of them are homeless. One has to make effort to try and find their families. We try our best to find their families. It's hurting because some patients die as paupers. I can say we are lucky because when these things happen we meet with the pastors and we see these things daily.

Tirisano reflected how her emotions are highly evoked at work when interacting with some patients. Her expression was: "Sometimes it is difficult at work because we do not connect with some patients. They do not take orders like they refuse to bath or to be bathed sometimes. I find them to be stubborn at times."

Sonto indicated that her position at work is essential and meaningful despite coming across adversities. She also raised motivational factors regarding the potential for personal development at work:

> Since my position at work is of a Centre Manager it is not the same as other managers who work in the supermarkets. Here we are dealing with lots of emotions. For example, my son was involved in a motor vehicle accident. Ever since, when I come across an unconscious person or when people cry for their family members I become reminded of my own son even though he is fine now. It is difficult to deal with dying patients.

Sonto further explored how her position at work is diverse as she also excels in other spheres:

> I help caregivers with offering total patient care, which entails admissions, assessments to ascertain if patients are correct candidates. I am also a family counsellor or systemic

counsellor as I provide counselling to children and adults, particularly bereaved families. I also do counselling and testing for HIV, that is, HCT. I assist with mentally challenged patients next door as I have previous work experience in a psychiatric hospital.

Similarly, it was evident from Sipho's point of view that there are possibilities to move from one position to another by stating that his position at work kept evolving:

My experience as a caregiver has changed over years. At first I was full-time or rather a permanent caregiver. I bathed patients, dressed their wounds and fed them. After four years I simultaneously worked with the terminally ill patients as well as patients who are mentally challenged in the same premises. It was a different experience from changing diapers or feeding patients. Sometimes I have to think within their parameters, that is, I have to be emotionally there for them. However, my role as a caregiver for the terminally ill and mentally challenged patients does not differ much because it is all about taking care of patients. I also plan for events like transporting patients to the zoo or circus shows.

It is evident that personal loss, disconnectedness and depression were experienced by participants and that they cannot avoid internalising their emotions. Mullan (1998) views a sense of loss experienced by caregivers prior to the actual death of the patient and views this as the primary source of the stress of caregiving. In a study conducted by Tichauya (2012) caregivers expressed having to make themselves strong especially when in company of care recipients, that is, most caregivers believed that showing real feelings of distress could perpetuate the condition of individuals living with HIV/AIDS.

Kanste, Miettunen and Kynga (2006) found that rewarding transformational leadership seems to protect from depersonalisation. They also reported that the relationship between leadership and burnout depends on situational factors of leadership, burnout or stress. For example, Tumelo concluded that she has not adapted, stating that her job was stressful because she had no freedom to do what she had been practising or had been taught as a qualified nurse. She shared her frustrations of working under someone because she felt she had no say and therefore she went with the flow. "I am working under someone and whatever she says is right, it is right indeed. I have to listen to her all the times."

Significance of the Length of Period in Service

The work experience of caregivers was an intrinsic theme that emerged as only one participant viewed it as fundamental. One of the participants who had extensive experience in nursing background explained that her experience of working with emergency cases particularly cancer patients was a better protective factor as they recovered speedily, unlike at the current hospice where patients die almost daily or their recovery is slow and also the context was described as depressing. Tumelo said:

> My job is stressful because I do not have the freedom to do what I have been practising or what I have been taught. I am working under somebody and whatever she says is right, it is right indeed. I have to listen to her all the time. It is quite depressing here; previously I worked with emergency cases and people recovered quickly. Here the recovery process is very slow. I am not used to working in such a place. The patients here die almost day after day. Previously I worked with a lot of cancer patients and in the pap-smear department. I had to come here because I am over age, had to leave even though the health minister said we could stay.

It is apparent that despite being exposed to working with recipients with chronic diseases for a long period of time, carers are still impacted in various ways, such as when recipients die. This is supported by the findings of the study conducted by Tichauya (2012) that the consequences of the death of care recipients, after all the effort of caring by the caregivers is another crucial challenge. Graaf (2011) argues that experience is a mediator of the stresses of working with traumatised people. Workers with low resilience levels tend to develop high levels of stress and trauma and give up their jobs and yet workers who remain to gain more experience are the ones who are likely develop higher levels of personal resilience.

Social Support

This category of individual resilience resources outlines how the caregivers' unique qualities interact with the environmental and broader social context to alleviate effects of unfavourable circumstances. Social support, determination and spiritual beliefs were found to

be protective factors in creating turning points, such factors as transcendence (replacing loss with gain), accommodating (deciding to relinquish), and self-understanding, service to persons with disabilities to enable individuals to gain meaning in their lives (De Chesnay & Anderson, 2008).

The majority of the participants at the Gauteng-based hospice reflected on the importance of working within clear boundaries in terms of their role as caregivers. In concurring with Stamm (2005) supervision has been identified as a significant enabling factor for caregivers. This conflicts with other contexts of caregiving where the caregivers appear frustrated because they feel that their voices are not heard by their superiors. For instance: "I am working under someone and whatever she says is right, it is right indeed. I have to listen to her all the time" (Tumelo). In the same way, Sonto reflected: "I feel unsupported at work." This also contrasts with Ungar (2008) finding that possessing good social and communication skills with peers and adults is a much needed protective mechanism.

Recognition and Rewarding of Caregivers

The participants gave an account of how they recognise that their job offers them a sense of reward regardless of the challenges they come across. They relayed various reasons for this:

> I like taking care of patients that is, providing care makes me happy moreover when patients recover and return home. When they come back to see us makes me even happier to realise that they have recovered, it means I have done something to another person (Kholofelo).

Sipho also expressed a similar sentiment: "I am fulfilled when patients come back to us after being discharged from the hospice to show us how well they have recovered."

"My job on its own is something I dreamt of, I believe is something that I love. It was a calling and I do not think that it is a mistake that I am here and it was not for the purpose of money" (Sonto). Lastly, Puleng: "I am happy where I am because I come far with nursing."

Some caregivers reported that the greatest rewards for their job are the fact that the organisation informed them that they would be offered training in palliative care. Schulz and Sherwood (2008) contend that most caregivers report that caregiving makes them feel good about themselves, in the sense that they are needed, and caregiving also gives meaning to their lives.

Organisational Resilience Resources

Definition of Roles: Seeking Clarity of Roles and Responsibility

Graaf (2011) maintains that an essential factor that seems to influence the caregivers' vulnerability is the degree to which roles are identified which is protective to both expectations of caregivers and patients. The findings of this study indicate that some participants saw the importance of the pragmatics of their job. There seemed to be a clear understanding of their routine and in how they execute their tasks. Tirisano described her work responsibilities by commenting: "I bed-bath patients, make their beds, dress their wounds, feed them and give them medication. We do health-talks and help them with exercising."

Participants explained how they interact with each other and some highlighted their over-involvement in their respective duties. "I arrive at work at seven in the morning and bed-bath only the patients who need help since some of them are able to bath themselves. I escort some patients to the clinic or hospital for doctor's appointments or follow-up. We do health talks to educate them about their sickness and the importance of taking medication. Devotion is spiritual; we hold spiritual services to encourage them because being in a hospice sometimes makes patients lose hope" (Kholofelo).

Tumelo spoke from a different angle suggesting that roles amongst employees must be distinctly defined because in her opinion the "hospice's protocols, rules and regulations, job descriptions and category must be very clear". She commented on the impact of the

health system in the South African context in her experience as a nurse and found caregiving close to what she did where nurses were now obsolete. This confirmed the confusion that emerged when Sonto described herself as a supervisor to the caregivers, a position that Tumelo also said she was holding. Role-definition may be viewed as a risk factor for the hospice, that is, protection and recovery factors of resilience can be best observed in the presence of risk factors because a system is demanded to stretch and to make adjustments due to finding itself in a position of being in jeopardy (Strauss, 2011), whereas in other contexts a clear understanding of role definition or clarity is a factor that protects against compassion stress and burnout (Miller, 2000).

Job Fulfillment

The ability of caregivers to derive pleasure from being able to work has been found to be apparent among most of them (Stamm, 2005). Although the majority of participants in the current study reported experiencing fulfillment and satisfaction in relation to their work some participants were dissatisfied. Because of the caregivers' background in nursing they still ensure that patients get the best care. The findings of this study highlight that even though the participants are challenged in their work environment, potential to acquire gratification was verbalised. Kholofelo contended that:

> I like nursing, especially taking care of patients, giving care makes me happy more especially when the patients recover and return home. When they come back to see us (this) makes me even happier to realise that they have recovered. It means I have done something right.

Sonto believed through this job she is living her aspirations and she views her job as more than just a job but a vocation. She further explored how challenges are not obstructing her to serve and help others in society:

> My job on its own is something I always dreamt of. I strongly believe it is something that I love. It was a calling and it is not a mistake that I am here. I am not doing this job for the

purpose of money. I face all these challenges but I do not see myself serving anywhere else other than this organisation.

Caring for patients for Sipho has offered him satisfaction and soundness. Furthermore, he described his job as restorative because it pleased him when patients return to their normal lives and recover:

> I am fulfilled at work, it is a development of healing because someone comes terminally ill and after three months they get well and be discharged. It is fulfilling when they come back to us after being discharged to show us how well they have become.

In contrast, issues of concern for some caregivers not achieving fulfillment at work related to lack of resources because of financial constraints and limited remuneration. This is evident in the following extract:

> My job is not fulfilling for me because the finances are not enough. They must improve some of the things like extending the kitchen to separate it from the wards. I also think lack of funds are giving them problems (Tirisano).

Similarly, Tumelo confessed: "My work is not fulfilling for me because it is lower than what my expectations are for a nursing sister. The salary I earn is too little." Consistent with Stamm (2005) on the Professional Quality of Life Scale in their previous research the findings revealed that higher scores on this scale represented greater satisfaction related to the ability of caregivers to be effective in their job.

Fear of Infections

The current study revealed that caregivers' perceptions of possible infection of diseases varied from person to person. Ungar (2006) confirms this in stating that what is taken to be adaptive in one context may be maladaptive in another. Therefore for some caregivers it is normal to be exposed to the environment in which people are ill as it is part of their job, whereas for some caregivers they need some form of adaptation. Some caregivers,

in the current study, did not feel entirely protected in terms of their health due to lack of equipment such as surgical gloves. Nonetheless, they mentioned that they still proceeded with their duties as required and improvised with the little equipment that they had. Tirisano expressed her concerns when she said: "They must improve some of the things like extending the kitchen. It needs to be separated from the wards so that cross infections can be controlled". Sonto further explained that: "We check if they don't have an infectious disease. If too sick they are moved away from other patients to prevent cross infections. I get the Social Worker to contact their family if the condition of the patient is very bad or send them to the hospital or if there is a need for oxygen".

It emerged in the study that previously two employees had passed on from tubercolosis-related symptoms and the co-ordinator was admitted at the hospital for heart problems. Puleng reflected: "A few years ago, two of our colleagues were deceased from TB and our co-ordinator was admitted for cardiac-related problems." This confirms De Chesnay and Anderson's (2008) findings where they elucidate that employees who work with ill people and patient visitors are vulnerable to infections.

Many caregivers are afraid that they may become infected with HIV and lack of knowledge about the disease, treatment, emergency situations and community resources often hampers Home and Community-Based Care (Van Dyk, 2012). Some participants implicitly highlighted the essentials of being protected from spreading diseases: "The kitchen needs to be extended, to be separated from the wards so cross-infections can be controlled" (Tirisano). Similarly, Sonto relayed:

> I physically assess the patients' illness and what they are suffering from. And their nutritional status as some of them requires soft diet and amongst other things we check if they are well hydrated. If they are very sick we assess if the disease is not contagious. If too ill we move them away from other patients to prevent cross-infection. I get the social worker to contact their families if the condition is deteriorating or send them to the hospital.

In the same way, Tichauya (2012) reports that fear of becoming infected with the virus makes the caring process difficult for most caregivers. Caregivers are sometimes referred to as "secondary patients," who need and deserve protection and guidance (Reinhard et al., 2008). Another risk factor is that in other instances caregivers of patients with HIV/AIDS are themselves infected and may be registered as clients of the organisation for which they work (Graaf, 2011). Contrary to a study conducted by Branscum (2010), caregivers reported poorer health than non-caregivers while others reported no significant physical health differences. Moremi (2012) argues that stressors that are unique to HIV/AIDS caregiving include fear for infection through occupational exposure to death and dying patients.

Coping strategies

Dealing with Occupational Stress

The following theme of talking with colleagues became evident in how the participants deal with work stress: "Talking helps; we have agreed as a team that we must talk through our difficulties" (Sonto). "I am sorry to say this, but I think there is too much stress here. We talk about it as colleagues and that can be comforting" (Tumelo). Similarly, Puleng relayed:

> I believe stress is part and parcel of one's life. I cope by talking about my frustrations to the others as well as my difficulties. At times we are offered counselling, I wanted to explain that we receive debriefing once or twice a month.

Participants also utilised the comfort of talking to allied professionals as a resource that assists to bounce back in challenging situations. Kholofelo reflected:

> There are periods when you feel down but at work they organise a pastor or counsellor. The social worker comes to the hospice once a week and talking to them helps. Generally I am not stressed at work unless financially. Usually when I am stresses I talk to someone.

Even though the majority of participants draw their strength from speaking to each other about their challenges, a few caregivers indicated how they utilise other available resources. Sipho stated:

> When I first started working here I took lots of pain but I learned to get that off my shoulders because when I get out of that gate I try to forget what happened at work as it can be toxic.

According to Branscum (2010) the manner in which people perceive stress differs in a multitude of ways in that some people still have a positive outlook on life despite adversities. Similarly, Schulz and Sherwood (2008) claim that recently researchers have focused not only on providing care as a cause of distress, but also on the caregiver's perception of how much the patient is suffering. In addition, Seligman (2002) believes that resilience exists when people are optimistic, have self-understanding, use humour in their lives, have a capacity for hard work, and possess the ability to cope with and find outlets for emotions. Similarly, Woodgate (1999) views resilience as an active process that develops internal resources for coping with stress. The current study resonates with the research in maintaining that the concept of increasing resilience through good coping skills is fundamental (De Chesnay & Anderson, 2008).

Employee Support

This category of organisational aspect focuses on the importance of supervision and access to consultation when needed by the caregivers. Most participants reported that in times of adversity they have identified communication about conflict as a protective factor. Kholofelo made the following comment: "Talking helps, we have agreed as a team that we must talk through our difficulties. For instance, if you have a conflict with someone address it immediately." Sonto stated: "Sometimes patients insult you by saying big-big things that are really-really upsetting. As soon as you talk to someone about the challenge it becomes better.

Alternatively as a team we would approach that person so the patients know we don't want people to do wrong things to us".

Lazarus and Folkman (1989) found that the coping strategies for caregivers were complex and were dependent not only upon the situation but also upon the individual's perception of the event. Even though Sonto resonates with her colleagues when they stated that talking to each other as colleagues was comforting. She maintained that talking to her husband at home sometimes was helpful although she chooses what she confides in as she is aware that her work problems can be harmful to her personal life.

Gahagan et al. (2004) contend that many caregivers claimed that emotional support in the form of empathy, appreciation and commiseration was an essential element of supportive relationships. In addition Gahagan et al. (2004) argue that due to intense emotional involvement with patients and the patients' families, caregivers' emotional involvement has been viewed as an aspect that increases vulnerability to burnout.

Rather, what seems important especially with challenges the caregivers might be facing, is to approach life's challenges with a positive frame of mind, a confidence that one can deal with the situation, and a repertoire of approaches. As reported by Tichauya (2012), caregivers filled ordinary events with positive meaning by pursuing and attaining important goals when encouraging the care recipients to take their treatment or seek medical advice.

Emotions and Feelings Encountered by the Caregivers

Negativity/ Feelings of Disconnection

The data indicated that the majority of the participants were not pleased with how some of the patients were disrespectful towards them and some were feeling disconnected from patients. According to Lin et al. (2011) negative caregiving experience was likely to be affected by caregivers' characteristics or by the interaction between caregivers and care

recipients. For example, a high level of distress was experienced by caregivers when care recipients display more problem behaviours or present greater dependency.

Tirisano expressed the following: "Sometimes we do not connect with some patients because they do not take orders such as bathing, I experience them as stubborn." Similarly, Tumelo said:

> Some patients are very rude and impatient. I feel they are unappreciative, you talk to them and they snap at you. It's like you do not know anymore which method of talking to use especially when you feel there's a need to help.

It was evident in Omodona's (2010) study that highly demanding workplace interactions may put considerable emotional burden on the caregivers and the most common emotional demand has been emotional exhaustion and disengagement.

Branscum (2010) confirms that caregiver emotional burden could lead to negative outcomes such as abuse. Shelton (2003) states that the caregivers' stressors could subject them to mental abuse such as discrimination. McCubbin and McCubbin (1996) are of the opinion that when there is crisis or a person is vulnerable, it becomes exacerbated when confronted by stressors. Branscum (2010) maintains that in his study caregivers of care-receivers with high levels of depression and behaviour disturbances were significantly more inclined to report increased level of subjective burden.

Feelings of Helplessness and Hopelessness

The findings of this study suggest that the participants of the hospice experience a wide range of feelings and emotions emanating from their experience as caregivers. Most participants highlighted the importance of their job practicalities such as: bathing patients, dressing them and their wounds, changing of patients' adult undergarments, and feeding them is in tandem with the expectation of providing emotional support to patients. Consistent with Dinat (2005), other hospices performed tasks such as washing and feeding the patients,

cleaning up the hospice, and making up the beds as they do in hospitals and still provided emotional support to the patients. The data revealed that the majority of participants have expressed feeling helpless when working with terminally ill patients. Similarly, Tichauya (2012) emphasises that from a psychological point of view, stress can cause feelings of hopelessness, helplessness, irritation, exhaustion and anxiety. Sonto confessed that dealing with one's own emotions was difficult:

> Here we are dealing with lots of emotions. For example, my son was involved in a motor vehicle accident, ever since, when I come across an unconscious person or when people cry for their family members I become reminded of my own son even though he is fine now. It is difficult to deal with dying patients.

Kholofelo acknowledged that when patients die she becomes emotional:

> You see a person every day. When they pass on it's like you are losing part of your life. You feel you did not do hard enough; you become emotional but try hard to stay strong and not to show your emotions.

Sonto's helplessness was also revealed from a different angle where she stated that: "Sometimes patients insult you by saying big-big things that are really-really upsetting." These findings are consistent with the literature reviewed earlier which indicated that caregivers face greater stress and mental health problems (Strauss, 2011).

Feelings of Disappointment

It was apparent from the findings that came out of this study that the participants expressed feeling disappointed by certain aspects at work and often they have to deal with abject poverty. One of the caregivers informed the researcher that in her experience of working with terminally ill patients most of the patients were homeless. She said: "One has to make an effort to find the patients' families, we try our best to find their families and it is hurtful because they are paupers" (Puleng).

The literature reviewed highlights that relationship attributes have been related to; greater caregiver depression, burden, and providing problematic care (Morse et al., 2011).

Feelings of Anger and Frustration

The findings demonstrated that some caregivers' experience of working at the hospice evoked emotions such as anger. Most participants expressed anger pertaining to being disrespected by patients and in other cases anger was directed to the health system and government. "We do not have equipment such as oxygen, no dressings for wounds and we have no own Doctor as a result we have to take patients to the hospitals or clinics." They expressed their frustrations in that they no longer know "which method of talking to use any more with patients" especially when they feel they wanted to enlighten or assist them. Sonto explained: "We have agreed as a team that if people have a conflict it must be addressed immediately. Patients understand that we do not approve of wrongful behaviour, therefore we approach them." Similarly, Tumelo revealed the difficulty of not being appreciated, "I feel I interact with patients accordingly but if they do not appreciate me for the service I offer them then it is a tough one".

As was found by Shebi (2006), caregiving can include distressing emotions. Furthermore, she noted that caregivers experienced an array of ambivalent emotions ranging from: shock, hurt, sadness, anger and eagerness. Caring for an individual with HIV/AIDS produces conflicting feelings in the carers (Tichauya, 2012).

Reinhard et al. (2008) argue that caregivers are hidden patients themselves with serious adverse physical and mental health consequences from their physically and emotionally demanding work as caregivers and consequently pay reduced attention to their own health and health care. Thus the current study highlights how susceptible caregivers caring for HIV/AIDS patients are to developing personal emotional distress and potential mental health problems.

Relationship Resilience Resources

Ecological Resources

Seccombe (2000) suggests that resiliency cannot be understood or improved in significant ways by merely focusing on the individual-level factors. Instead, careful attention must be paid to the structural deficiency in societies and to the social policies that systems need in order to become stronger, more competent, and better functioning in adverse situations. This is a particular emphasis in the current study which promotes a theoretical orientation to view caregiving from an ecological stance.

The literature reviewed earlier demonstrated that caregiver stress has been known to carry over into relationships with: spouses, children, work colleagues, and even to the member for whom they were providing care (Branscum, 2010). Similarly, MacDermid et al. (2008) have noted a shift from viewing resilience individualistically to adopting a collective stance as a lens. The ecological perspective's focus is precisely on the individuals' interactions with their environment or broader influences which hold the potential to promote resilience.

Familial Resources

The data of the participants in this study revealed that most participants' social lives go through severe changes due to the tremendous additional workload of providing care. The data also revealed however that the majority of participants draw support from their family members. Yet participants voiced that they tried to avoid involving their family at all times in their work-related stress seeing it as potentially harmful. As was found by Aggleton and Parker (2002) the impact of the HIV/AIDS epidemic on: individuals, households, family and friendship networks are deemed to be serious. Furthermore Bronfenbrenner (1979) states that interactions with others and the environment are key to development and that all individuals experience more than one type of environment. Sonto demonstrated this:

> I speak to my husband about my frustrations but I don't want to scare him. But when I'm tired sometimes he cooks for us as a family. He listens but the problem is I cannot tell him everything concerning the death of patients and that their family members were crying for them. It's not pleasant to often hear about dying people.

This was confirmed by Gahagan et al. (2004) where caregivers frequently identified exhaustion and loss of stamina and strength related to provision of care. Tumelo reflected: "Because there is too much stress here we talk about it with colleagues and I get support at home and have people who are encouraging me." It was evident that some of the participants not only involve their families in their hardships at work but also utilise available resources in the system. This is evident in the following extract: "There are periods where you feel down but at work they organise a pastor or counsellor. The social worker comes once a week to the hospice and speaking to her helps" (Kholofelo). Similarly, a study conducted by Graaf (2011) confirms that access to staff support and counselling is an important factor in mitigating distress. Weathering a crisis together, a family or group can emerge more loving, stronger, and more resourceful in meeting future challenges (Walsh, 1998; White et al., 2004).

According to Walsh (2000), what mental health professionals can do is to create a safe haven for family and community members to share both deep pain and positive strivings. In addition, resilience is viewed as a relational process that manifests itself and is observable in a system and over time. This view is supported by leading theorists in the family resilience field (Hawley & De Haan, 1996; McCubbin & McCubbin, 1996; Walsh, 1996).

Community Resilience Resources

    Access to Resources

        Insufficient Funding

The findings of this study revealed that the Gauteng-based hospice is a non-governmental organisation and therefore it has to generate its own funding. The participants have highlighted that this creates a strain for them to fulfill their duties as there is lack of medical resources. Almost all of the participants stated that they do not have essential equipment such as: oxygen, surgical gloves and toiletries. They reported that work can be de-motivating under such conditions. Nonetheless they still proceed because of their passion for serving people. Tumelo stated:

> We have no resources. I feel we should get a list of what we need. Like now I am still compiling a list of everything that we need. If the health department or nurses come to our premises we have to share the bathroom basins with the patients. We also need equipment like oxygen.

Kholofelo reflected:

> Because this is a hospice and an NGO, the organisation depends on donations. We do not have equipments such as oxygen, no dressings for wounds. We have no own medical doctor as a result we have to take patients to the hospital or clinic. As for the staff they try to provide us with medical gloves and masks but it is not enough.

Along similar lines, Vogel (2011) emphasised that the attending physician listed with the hospice who is not a hospice employee or volunteer may have intense or minimal involvement with the hospice patients.

Additionally, participants highlighted how the organisation being resource-strapped influenced them as caregivers: "in terms of the equipment, (we) rely heavily on donations, there are no dressings for patients and many things. We have complaints today and every day. We do not have benefits for ourselves and patients" (Puleng). Tirisano further stated that, "We do not have oxygen or suction machines or even enough BP machines. There are no

sufficient resources, for example, sometimes there is a shortage of toiletry in order to be able to bath patients." This finding is consistent with that of Armstrong (2000) that the carers lack resources to do their work effectively namely: stationery materials for record-keeping and basic medical supplies such as rubber gloves.

The participants also indicated the importance of extending the hospice to assist in controlling cross-infections. "I think lack of funds is giving them problems." This supports Setswe, Davids and Human Sciences Research Council (2009) who claimed that Community Home-Based Care has: psychological, social, economic and physical needs which need to be met to enable caregivers to do their care-giving work, effectively. Dinat (2005) elucidates that some caregivers, because of a shortage of kits and gloves, provided encouragement to patients to access primary health clinics for assistance.

Inadequate Remuneration

The participants at the Gauteng-based hospice emphasised their concerns regarding the fact that their salary was not sufficient. However, they have stated that in spite of this they still proceed with their prospective duties because they are passionate about their jobs. Studies have revealed that caregiving has an impact on: the health, work and leisure, and the need for adequate transportation and finances in the caregivers' and the recipients' lives (Gahagan et al., 2004). Along with Reinhard et al. (2008), some caregivers who attempt to balance caregiving with their other activities such as work, family and leisure, may find it difficult to focus on the positive aspects of caregiving and often experience more negative reactions such as an increased sense of burden.

Another risk factor that was identified through the participants in this study was the fact their salary is not paid on time. This was highlighted by the following extract: "Sometimes we do not get our salary on time. Despite the fact that we are back paid, it is an inconvenience for us (Tirisano). Puleng stated: "We do not have benefits for ourselves and

patients." Similarly, Kholofelo indicated: "Generally, I am not stressed at work unless financially".

It was also evident in Sonto's reflection that she feels that not all caregivers are not well looked after by the organisation and they are not provided with important benefits like a housing subsidy. Her reflection also raises a question regarding xenophobia in relation to employee benefits:

> My husband recently lost a job, I was very sad when I was refused accommodation by my superiors in one of a block of flats that they own. I was told as a foreigner I do not qualify for accommodation. Where I stay rent is R4000 per month and my earnings are six thousand rand which is not enough. I still have to pay for electricity and transport. My children attend school under this organisation and some of my colleagues' children attend for free. I am hurt because I feel unsupported.

Access to Training

In the wake of devastating trauma, individuals can be helped to regain hope in their future possibilities (Walsh, 2007). This approach is guided by a bio-psycho-social systems orientation, viewing problems and their solutions in view of multiple recursive influences involving individuals, families, and larger social systems (Walsh, 2002). According to Black and Lobo (2008), resilience entails more than surviving a crisis, but also offers the potential for growth out of adversity. There is a drive for participants to equip themselves academically but they stated that finances are a hindrance. Sonto reflected:

> Myself as a person I want to learn more on how to take care of patients. I also need more training this year. For example, I plan to study a course in palliative care where I can specialise after I complete a higher certificate in management which I am busy with now. We were informed at work that there would be a three-month course in palliative care offered to us. If that happens I will be a happy woman at the end of the year.

Consistent with Dinat's findings (2005), in Soweto, South Africa, home-based-caregivers expressed the importance of their role, however, were under-resourced. In

addition, there were complaints that home based care (HBC) is inadequately funded.

Resilience is a resource for conquering difficulties, which often manifests in individuals

having hope and a positive outlook. In the current study, Kholofelo expressed how she

wished to equip herself by taking herself for further studying but explained that finances were

a setback: "Things change, new treatments are discovered and it is important to try not to

focus on the old syllabus. It would be better to attend courses by trying to take myself to

school." Tirisano relayed that she would like to complete some courses in the field of

nursing.

Cultural Resilience Resources

Spiritual Resilience Resources

The participants found that faith and prayer were protective factors that helped them

in the betterment of their life circumstances. According to Morris (2012) cultural resilience is

a concept that predates the discovery of people in that; our worldview is the cultural lens

through which we understand where we come from, where we are today and where we are

going. Kholofelo emphasised:

> Devotion is spiritual, we hold spiritual services to encourage patients because being in a hospice sometimes can cause patients to lose hope. So we do spirituality daily to encourage them that God is with them they are not alone and we also need that as workers. There are periods where you feel down but at work they organise a pastor or counsellor.

Studies have revealed that caring for people with a terminal disease is a: physical,

emotional and sometimes spiritual undertaking that places a great deal of pressure on the

coping resources of the caregiver Naidu (2005). The findings of this study have indicated that

the caregivers' worldview and reality is influenced by their backgrounds and belief systems

as well as religious practices. Strauss (2011) argues convincingly that incorporating religious

and spiritual practices as part of coping behaviours assists management of distressing events.

Tirisano indicated: "I put my faith in God and it gives me strength." Puleng stated: "The pastors usually come on Saturdays, usually to the patients and not to us. Maybe if we also saw them it would have helped to some extent." There were inconsistencies in terms of whether the pastor counselled the patients only or in addition to the caregivers.

Some participants also wished to be uplifted spiritually by the pastor. However, most caregivers had a sense of connectedness to their creator (God) which gave them hope and meaning to their lives and as such they are able to encourage patients. "Devotion is spiritual; we hold spiritual services to encourage patients. Being in the hospice sometimes causes patients to lose hope. So we do spirituality every day to encourage them that God is with them, they are not alone" (Sonto). A study conducted by Weller (2009) elucidates that religious or spiritual involvement provides psychological advantages which helps to change an individual's state of mind and has been associated with optimism and hopefulness.

Discussion of Findings

The motivation for this study evolved from a personal and a professional need as a student clinical psychologist to comprehend the resilience of caregivers from a Gauteng-based hospice with patients living with HIV/AIDS. The researcher chose social constructionism as a field of knowledge as it traces the origin of knowledge, meaning or understanding to human relationships (Gergen, 2008). This epistemology corresponds well with the qualitative research method that was utilised in this study as it allowed flexibility and the experiences of caregivers to be discussed in detail (Terre Blanche et al., 2006).

Making use of semi-structured interviews, focusing on caregivers' experiences in working with terminally ill HIV/AIDS patients, it emerged that each caregiver viewed the caring experience from different levels of perspective. There were commonalities and differentiation in how caregivers shared their stories. The findings of this study revealed that caregivers expressed difficulties in adjusting to their work as losing patients often left them

with a sense of personal loss. The caregivers expressed feeling disempowered and somewhat defeated when care recipients die. This coincides with the literature reviewed by Tichauya (2012) that fear of death of those that caregivers care for is a constant threat. Furthermore, Moremi (2012) contends that stressors that are unique to HIV/AIDS caregiving include fear of infection through occupational exposure to death and dying patients.

Hill et al. (2007) suggest that when people experience any active adversity they are especially in need of resilience-protecting factors. Previous studies have viewed experience as a possible mediating factor of the stresses of working with traumatised people (Miller, 2000). However, the findings at the Gauteng-based hospice, the focus of the current study, revealed that very few carers viewed experience as a protective factor, whereas others found that no significant effect exists. Graaf (2011) claims that caregivers who develop higher levels of personal resilience are the ones who remain in their work to gain more experience as opposed to those who give up their jobs.

Role precision is not a factor that was of great concern for most caregivers of the Gauteng-based hospice. Only one participant expressed the importance of role definitions. This one finding remains congruent with that of Miller (2000) that a clear understanding of role definitions is a factor that protects against compassion stress and burnout.

The degree to which participants of this current study are fulfilled in their work varies. Some caregivers explained that they received fulfilment and satisfaction in their job (Stamm, 2005). In contrast, the otherparticipants were not fulfilled in areas such as remuneration. The findings have indicated the importance of: economic, physical, and psychosocial support from families, loved ones and health-care workers (Tichauya, 2012). This is confirmed by Uys (2003) who found that community caregivers reported financial constraints as a challenge to their work. Uys (2003) further reported that stress experienced in HIV/AIDS caregiving is inherent in the nature of the work itself. In the same way, Campbell,

Nair and Maimane (2005) contend that economic stress emanates from the fact that caregivers' earnings are meagre and do not meet their basic needs. The majority of participants experienced a mixture of feelings and ambivalence ranging from: feeling helpless, angry and disappointed. Similarly, Shebi (2006) noted that caring increases distressing emotions. Furthermore, she noted that caregivers experienced a lot of emotions ranging from: shock, hurt, sadness, anger and eagerness. Nonetheless, some participants at the Gauteng-based hospice voiced still having passion in rendering their services. This finding is coincides with previous research (Tichauya, 2012). Despite viewing the caring process as challenging and emotionally taxing, the participants were able to see it in a positive way.

The findings of this study revealed that if the background or work environment is not rich and good at support, the participants find it difficult to approach their challenges by employing efficient problem-solving strategies as coping measures (Moremi, 2012). Participants in the current study reported employing various techniques or help channels as coping strategies. They stated that drawing strength from each other as colleagues was an effective coping strategy. Primarily, most participants felt the need to be supported at work which was viewed as a potential motivating and protective factor. Tichauya (2012) found that support was mostly offered to the care recipients and not so much to the caregivers.

According to Lazarus and Folkman (1989) coping mechanisms or strategies such as spirituality as well as gathering support from other members in the same situation through discussions and support group facilitation were employed by most caregivers. The findings of this study have indicated that the caregivers' worldview and reality is influenced by their personal and family backgrounds as well as belief systems such as religion. In support, Strauss (2011) found that incorporating religious and spiritual practices as part of coping behaviours assist management of distressing events.

It was noted from the findings of this study that working in a context of people often dying affects caregivers within their family life. This notion is supported by Walsh (2003) who highlights that problems are seen as resulting from an interaction of individual and family vulnerability in the impact of stressful life experiences and social contexts.

Despite the challenges voiced by the participants, the findings of the current study showed that most participants expressed the fundamental of equipping themselves through education. After all, according to Black and Lobo (2008), resilience entails more than merely surviving a crisis, but also offers the potential for growth out of adversity.

Conclusion

This chapter offered an account of the data analysis and findings that emanated from the semi-structured interviews. Themes and sub-themes were identified and they were elucidated by the verbatim responses given by the participants. Following this the findings of caregivers' perceptions and experiences regarding their resilience in working with patients living with HIV/AIDS were discussed in relation to other key studies.

CHAPTER 5

CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

Introduction

The previous chapter presented the findings of the study. The current chapter is an integrated discussion of the: overall findings, conclusions, implications, recommendations and limitations of the study. The focus of this study was to explore the resilience of the caregivers of the Gauteng-based hospice with patients living with HIV/AIDS. This study indicates that the caregivers were resilient in various spheres of life during times of adversity.

Implications of the Findings

The outcome of the findings from interviews with participants highlights that there is a great need for support of the organisation. The caregivers were adamant that if sufficient support was offered to the hospice, unnecessary strain could be avoided in their experiences as caregivers, particularly with terminally ill patients. Kumpfer (1999) argues that the environmental context of stressors and support can help the individual through psychosocial facilitation processes.

The findings of this study also indicate that caregivers utilise effective coping strategies such as: family support, support from colleagues, and spirituality. The caregivers found these strategies positive and enhancing of their coping abilities at work. However, caregivers strongly voiced the need for financial support and access to essential resources for their benefit and the benefit of the patients. As such, the above-mentioned implications have impacted not only the caregivers but also their loved ones and the South African society at large.

Bronfenbrenner (1979) suggests that interactions with others and the environment are the key to development. In addition, the caregivers' perspective is guided by a bio-psycho-social systems orientation, seeing problems and their solutions in view of multiple recursive influences involving individuals, families, and larger social systems (Walsh, 2002).

Notably, the caregivers at the Gauteng-based hospice saw the importance of adequate interventions and assistance to enhance their caregiving work for the benefit of HIV/AIDS patients. The implications of this study in the South African context indicate that caregivers have to be guaranteed improved facilities and to ensure that they are catered for to meet their personal needs and the needs of the patients that they serve.

Strengths of the Study

The primary strength of the study is that it has served to highlight the experience and important aspects of caregiving for patients living with HIV/AIDS within an urban South African context where HIV/.AIDS is an apparent health challenge. Regardless of the fact that the Gauteng-based hospice is situated in an urban area, hospices in the communities tend to be neglected for research studies especially since they are funded by non-governmental organisations. The participants in this study made it easier for the research to proceed fruitfully as there seemed to be unity amongst them. The caregivers' level of maturity and work experience made it possible for rich and comprehensive information to be gathered.

Limitations of the Study

Despite the fact that this study contributed to adding value to the review of the literature, a few limitations that were extricated need to be taken into consideration. The fact that there were six participants in this study means that the findings may not necessarily be comprehensively informative to the entire population of the caregivers as a whole within South Africa or internationally. However, the outcome of the qualitative study has aimed to provide a sincere understanding of the experiences of caregivers from their own perspective as a contribution to further studies which value the voice of caregivers.

The gender of the participants also needs to be considered. According to Graaf (2011) most caregiving in the context of working in a hospice with terminally ill patients is strongly linked to gender issues. Furthermore, studies have shown that 68% of caregivers of people

with HIV/AIDS and related illnesses in South Africa are predominantly women and girls. This was a similar case for this study where only one African male was a participant. Reinhard et al. (2008) further argue that in most caregiving situations male caregivers engage in more complex tasks such as managing finances and arranging care as well as more direct assistance with personal care.

Lastly, the use of a tape recorder might have had a negative impact on or hindered the findings as well as intimate interpersonal relationships with the participants. It is hoped that this study will assist in the review of research in the South African context as most other research stems from an international Western perspective.

Recommendations

It is essential to note that all of the participants were exclusively black Africans. It is therefore recommended that should this study be replicated that the participants be selected from across cultures.

It would be of benefit for caregivers to be offered training in problem-solving skills. Although the caregivers of the Gauteng-based hospice have a regular social worker, there is a strong need for the caregivers to utilise other channels of assistance and support structures available in their communities to deal with stress.

Training programmes should be provided to motivate and help caregivers expand themselves and to assure them of intellectual growth especially since most of them have a background in nursing. In the area of finances the NGOs can be encouraged to intensify money-generating projects including fundraising. Issues of remuneration require to be addressed to try and reduce the impact of stressors. It is also recommended that caregivers be encouraged to register with the relevant professional bodies for control purposes and to protect them against abuse.

Concluding Remarks

The purpose of this study was to investigate the resilience of caregivers at a Gauteng-based hospice with patients living with HIV/AIDS. The study was able to underscore the challenges and rewarding factors of caregiving from the caregivers' perspective. In spite of the difficulties encountered by the caregivers in caring for patients who are terminally ill and deemed to have a short life-span, the caregivers also delight in serving patients and feel rewarded when some of them recover.

Nonetheless support is constantly needed to help caregivers deal with the challenges of caregiving. Intervention from various sectors such as: government, public petition support, adequate professional support, access to resources and reasonable remuneration are a necessity to prevent unnecessary environmental stressors

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Department Of Psychology

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APPENDIX A: INTERVIEW SCHEDULE

(**INTERVIEW SCHEDULE**)

These questions are for the purpose of clarification.

1. Tell me about your experience of caregiving at the hospice? (Armstrong, 2000).
2. Can you explain where you find it difficult in terms of your work and where it is fulfilling for you? (Armstrong, 2000).
3. In your opinion how does caregiving of patients living with HIV/AIDS different to patients who are not living with HIV/AIDS? (Reinhard, Given, Petlick, & Bernis, 2008).
4. In times of stress what helps you to bounce back or cope? (UNIAIDS, 2000).
5. What are your expectations of this organisation? (Shaller, 2007).

APPENDIX B: LETTER REQUESTING PERMISSION TO CONDUCT RESEARCH

Dear sir/madam

My name is Rakgadi Mokoena I am currently completing a research report in fulfillment of my master's degree in clinical psychology at the University of South Africa. This research aims to describe the resilience of the caregivers at the hospice with patients living with HIV/AIDS. This study will contribute to the discipline of psychology to gain an in-depth understanding of what it means for the caregivers to work in the environment where patients die on a regular basis.

I hereby ask permission to access employees who are willing to participate in my study. All volunteering participants in the study will remain anonymous in that, while their words will be made known, their identities will remain confidential. The interviewing process will take place for approximately 60 minutes. Interviewees may refuse to answer any question and may withdraw at any point that they wish. Non-participation or withdrawal in the study will not have any negative consequences for you in any way.

Debriefing and information resources will be provided to the organisation. Each interview will be audio recorded and later transcribed. The transcriptions may be included in the appendix of the final work with all identifying remarks and names changed. General feedback regarding the study's outcomes will be made available to all participants who are interested.

Your organisation is in no way required to participate in this study. If you have any queries do not hesitate to ask me. It is necessary for me to obtain your informed consent before I can begin the study.

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APPENDIX C: INFORMATION LETTER TO PARTICIPANT

Dear Potential participant

My name is Rakgadi Mokoena I am currently completing a research report in fulfillment of my master's degree in clinical psychology at the University of South Africa. This research aims to explore on the experiences of the caregivers particularly within a hospice working with HIV/AIDS patients. Please note that all volunteering participants in the study will remain anonymous in that, while their words will be made known, their identities will remain confidential. The interviewing process will take place for approximately 60 minutes. You may refuse to answer any question and may withdraw at any point that they wish. Should you not wish to partake in the study or feel you want to withdraw it will not have any negative consequences or implications. Some emotions might be evoked during the process of gathering data and in such instances contact details will be provided for debriefing options. Each interview is to be audio recorded and later transcribed. The transcriptions or extracts of the transcriptions will be included in the appendix of the final work with all identifying remarks and names changed. General feedback regarding the study's outcomes will be made available to those participants interested.

You are in no way required to participate in this study. If you have any queries do not hesitate to ask me. It is necessary for me to obtain your informed consent before I can begin the study.

Your support is greatly appreciated.

Yours faithfully,

_____
Researcher: Mrs. Rakgadi Mokoena
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_____
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_____
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APPENDIX D: LETTER OF PARTICIPANT CONSENT

Dear Participant

Participation in this study is allowed strictly and only on the explicit understanding of the following conditions. The researcher undertakes to maintain confidentiality and anonymity, as far as possible, as outlined by her governing board, the Health Professions Council of South Africa.

You are in no way required to participate in this study, and you may withdraw from the study. The interview will be audio recorded and transcribed. Please be informed that the interviews will be recorded and notes will be taken. Recordings will be kept in a locked cabinet and destroyed after five years. All identifying details from the quoted extracts from the transcription will be removed prior to publication. Your signature below indicates that you understand and consent to the above conditions. It is necessary for me to obtain your informed consent before I can begin the study.

Thank you for your support.

Yours faithfully

_____

Researcher: Mrs. Rakgadi Mokoena
rakgadi@bakwenamedia.co.za

Name of Participant   _____

Signature of Participant   _____

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Astute Editing and Research

To Whom It May Concern

APPENDIX E: CERTIFICATE OF EDITING

Dear Sir/Madam,

This is to certify that I have fully edited the MA thesis of Ms Rakgadi Mokoena entitled "The Resilience of Caregivers at a Gauteng-Based Hospice with Patients Living with HIV/AIDS"for the University of South Africa. The text was checked for style, clarity and ease of reading, grammar and usage, spelling and punctuation, consistency in the use of text and figures in illustrations and tables, completeness and consistency in references, consistency in page numbering, headers and footers and suggestions were offered. I make no pretension to have improved the intellectual content of the thesis and did not rewrite any text. I presumed the text was in final form when I edited it. My suggestions are to be accepted or rejected by the author. The author effected the final changes herself.

Yours sincerely,

C.D. Schutte (D Littet Phil, Full Member, Professional Editors' Group)

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