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The impact of caring for terminally ill patients on caregivers at Sparrow Ministries Hospice in relation to compassion satisfaction, secondary traumatic stress and burnout

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The impact of caring for terminally ill patients on caregivers at Sparrow Ministries Hospice in relation to compassion satisfaction, secondary traumatic stress and burnout.

A report on a research study presented to

The Department of Social Work

School of Human and Community Development

Faculty of Humanities

University of the Witwatersrand

In partial fulfilment of the requirements for the degree Masters of Arts in Industrial Social Work.

Mmatapa Adelaide Mangena

March 2015

DECLARATION

I hereby declare that this research report is my own work and that I have given full acknowledgement to the sources I have used in the report.

Mmatapa Adelaide Mangena	Date

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ABSTRACT

The HIV/AIDS pandemic in South Africa has become a health care challenge with the high rate of people living with the illness and needing hospice care (Zimmerman, 2001). According to Munley (2006), palliative care is mostly provided by Non Profit Organisations (NPOs) who rely mostly on funding from private organisations and donations. Caregivers working under NPOS are usually faced with challenges such as lack of resources which might lead to them experiencing compassion fatigue, secondary traumatic stress and burnout. The primary aim of the study was to measure the levels of compassion satisfaction, secondary traumatic stress and burnout experienced by caregivers caring for terminally ill patients and HIV/AIDS patients at Sparrow Ministries Hospice. The sample comprised 15 caregivers employed at Sparrow Ministries Hospice who have been employed at the organisation for more than six months. The study combined both quantitative and qualitative research designs referred to as mixed methods research design. (Cresswell, 2007). A semi-structured interview schedule and the Professional Quality of Life (ProQol) Scale adopted from Hudnall Stamm, (2009) were utilised to collect data. The results were analysed using Thematic Content Analysis (TCA) and descriptive statistics. The results of the study, both qualitative and quantitative, indicate that more than half of the participants experienced high compassion satisfaction with average to low burnout and secondary traumatic stress.

In conclusion, awareness of secondary traumatic stress, compassion fatigue and burnout in caregivers might help the management develop strategies that may prevent caregivers from suffering from these. Caregivers might also need to develop awareness of the impact the work they do caring for terminally ill HIV/AIDS has on both their professional and their personal lives. The realisation by caregivers might assist them in not only focusing on issues with organisational structure, but also on better caring for their emotional wellbeing.

Keywords: HIV/AIDS, trauma, secondary trauma, compassion fatigue, burnout, compassion satisfaction, caregiver, palliative care.

TABLE OF CONTENTS

DECLARATION ..... **II**

ACKNOWLEDGEMENTS ..... **III**

ABSTRACT ..... **IV**

CHAPTER ONE **10**

INTRODUCTION **10**

1.1 STATEMENT OF THE PROBLEM **10**

1.2 RATIONALE FOR THE STUDY **11**

1.3 RESEARCH QUESTIONS **13**

1.4 THE PRIMARY AIM OF THE STUDY **13**

1.5 SECONDARY OBJECTIVES OF THE STUDY **13**

1.6 RESEARCH DESIGN **13**

1.7 DEFINITIONS OF KEY CONCEPTS **14**

1.8 STRUCTURE OF THE RESEARCH REPORT **15**

CHAPTER TWO **17**

INTRODUCTION **17**

2.1 DISTINCTION BETWEEN SECONDARY TRAUMATIC STRESS, COMPASSION SATISFACTION AND BURNOUT **18**

2.1.1 SECONDARY TRAUMATIC STRESS 19

2.1.2 COMPASSION FATIGUE 19

2.1.3 COMPASSION SATISFACTION 20

2.1.4 BURNOUT 21

2.2 SYMPTOMS OF COMPASSION FATIGUE, SECONDARY TRAUMATIC STRESS AND BURNOUT **24**

2.3 HOSPICE CARE **26**

2.4 THE CHALLENGES WITH HOSPICE CARE **27**

2.5 ROLES AND RESPONSIBILITIES OF CAREGIVERS IN HOSPICE CARE **27**

2.6 THE IMPACT OF CARING FOR TERMINALLY ILL HIV/AIDS PATIENTS ON CAREGIVERS **28**

2.7 CAREGIVERS' COPING STRATEGIES IN DEALING WITH SECONDARY TRAUMATIC STRESS, COMPASSION FATIGUE AND BURNOUT 30

2.7.1 PERSONAL COPING STRATEGIES 30

2.7.2 PROFESSIONAL COPING STRATEGIES 31

2.7.3 ORGANISATIONAL SUPPORT 32

2.8 CONCLUSION 34

2.9 THEORETICAL FRAMEWORK 34

2.9.1 INTRODUCTION 34

2.9.2 SECONDARY TRAUMATIC STRESS A CHALLENGE FOR CAREGIVERS 35

2.9.3 PROFESSIONAL QUALITY OF LIFE AND SECONDARY TRAUMATIC STRESS 35

2.9.4 CONCLUSION 36

CHAPTER 3 37

INTRODUCTION 37

3.1 RESEARCH DESIGN 37

3.2 RESEARCH METHODOLOGY 38

3.2.1 POPULATION AND SAMPLE 38

3.2.2 SAMPLING PROCEDURE 39

3.3.3 RESEARCH INSTRUMENTATION 39

3.3 PILOT STUDY 40

3.3.1 DATA COLLECTION 40

3.3.2 DATA ANALYSIS 41

3.3.3 THEMATIC CONTENT ANALYSIS (TCA) 42

3.3.4 DESCRIPTIVE STATISTICS 42

3.4 RELIABILITY AND VALIDITY 42

3.4.1 RELIABILITY 42

3.4.2 VALIDITY 43

3.4.3 CONFORMABILITY 44

3.4.4 TRANSFERABILITY 44

3.4.5 CREDIBILITY 45

3.5 ETHICAL CONSIDERATIONS 45

3.6 LIMITATIONS OF THE STUDY **46**

3.7 CONCLUSION **47**

CHAPTER 4 ..... **48**

INTRODUCTION **48**

4.1 DISCUSSION OF FINDINGS **48**

4.1.1 DEMOGRAPHIC PROFILE *48*

4.1.1.1 Gender of Participants 48

4.1.1.2 Age of Participants 49

4.1.1.3 Race of Participants 50

4.1.1.4 Marital status of participants 50

4.1.1.5 Type of training received 50

4.1.2 COMPASSION SATISFACTION 53

4.1.2.1 Noticing Improvement In Seriously Ill Patients *55*

4.1.2.2 Seeing Families Of The Patient Happy And Grateful *56*

4.1.2.3 Working With Children *57*

4.1.2.4 Combating the Effects Of HIV/AIDS *57*

4.1.3 BURNOUT 59

4.1.3.1 The Caregivers' Understanding Of The Concept Of Burnout 59

4.1.3.2 Emotional Exhaustion *61*

4.1.3.3 Cynicism *62*

4.1.3.4 Personal Efficacy *64*

4.1.3.5 Signs And Symptoms Of Burnout *65*

4.1.4 *CAREGIVERS' PERSONAL COPING STRATEGIES IN DEALING WITH COMPASSION FATIGUE, SECONDARY TRAUMATIC STRESS AND BURNOUT* **66**

4.1.4 Personal Coping Strategies *67*

4.1.5 Support Systems *67*

4.1.6 Activities to relieve stress and burnout *67*

4.1.5 COMPASSION FATIGUE 68

4.1.5.1 Challenging Factors In Caring For People Living With HIV/AIDS *68*

4.1.5.2 A Significant Shift In The Level Of Compassion *69*

4.1.5.3 Effects Of A Shift In The Level Of Compassion *71*

4.1.5.4 Work-Life Balance *71*

4.1.6 SECONDARY TRAUMATIC STRESS 72

4.1.7 PROFESSIONAL SUPPORT SERVICES OFFERED BY THE HOSPICE TO CAREGIVERS IN DEALING WITH BURNOUT. 75

4.1.7.1 Availability Of Support Services *75*

4.1.7.2 Knowledge About The Services Rendered *76*

4.1.7.3 Accessibility Of Services *76*

4.1.7.4 Addressing Challenges Faced By Hospice Caregivers *77*

4.1.7.5 Remunerations Policies And Procedures *77*

4.1.7.6 Incentives And Recognition Of Good Work *77*

4.2 CONCLUSION **79**

CHAPTER 5 ..... **81**

INTRODUCTION **81**

5.1 MAIN FINDINGS **81**

5.2 CONCLUSION **85**

5.3 RECOMMENDATIONS **85**

REFERENCES **88**

APPENDICES **94**

APPENDIX A: PARTICIPANT INFORMATION FORM **94**

APPENDIX B: CONSENT FORM FOR PARTICIPATION IN THE STUDY **95**

APPENDIX C: CONSENT FORM FOR AUDIO-TAPING OF THE INTERVIEW **96**

APPENDIX D: SEMI-STRUCTURED INTERVIEW SCHEDULE **97**

APPENDIX E: PROFESSIONAL QUALITY OF LIFE SCALE (PROQOL) (2009) **102**

LIST OF FIGURES

Figure 1: Age ranges of the participants (N=15) 49
Figure 2: Training received by the participants (N=15) 51
Figure 3: Number of caregivers and their level of compassion satisfaction (N=15) 55
Figure 4: Number of participants and their level of burnout (N=15) 60
Figure 5: Number of caregivers and their level of STS (N=15) 74

LIST OF TABLES

Table 1: Emerging themes and sub-themes from semi-structured interview (N=15)..... 52
Table 2: Participants' responses on comparison satisfaction (N=15)..... 54
Table 3 Levels of burnout experienced by the respondents as measured using the ProQol scale..... 59
Table 4 Caregivers' responses regarding secondary traumatic stress..... 73

CHAPTER ONE

INTRODUCTION

HIV/AIDS in the South African context has become a predominant focus; as a result the need for palliative care has become an important service. According to Uys (2003) in a country such as South Africa with such high rates of HIV/AIDS infections, palliative care became an urgent valuable service needed to cater for terminally ill patients by managing their pain and creating a comfortable environment in the final stages of their illness. This study was meant to give an insight into some of the challenges faced by caregivers working in palliative care, in particular with HIV/AIDS terminally ill patients. The main objective of the study was to measure the impact of caring for terminally ill patients on caregivers at hospice in relation to burnout, compassion satisfaction and secondary traumatic stress.

1.1 STATEMENT OF THE PROBLEM

In 2012, an estimated 6.1 million people globally were living with HIV, with 240 000 South Africans dying from AIDS-related illnesses annually. With such high rates of people infected and living with HIV/AIDS, South Africa has been identified as one of the countries with the largest number of people living with the disease (UNAIDS Report, 2012).

According to Wright (2004), formal public health care facilities in South Africa providing health care were considered to have poor facilities and lack of adequate resources, and as a result were seen to be providing poor services. As a result, institutions offering palliative care became a valuable resource for the health care system. The majority of such organisations operate as NPOs relying mainly on minimal government funding. The lack of funding for hospices poses a challenge of lack of resources and manpower to render proper palliative care services. Most of these NPOs utilise caregivers to provide care for terminally ill patients. Often the implications of using caregivers in poorly funded NPOs means that the caregivers, although trained, find themselves working in challenging and demanding working environments with minimal training (Bell & Richards, 2000).

As mentioned earlier, a hospice provides care for terminally ill patients in the last stages of their illness. Caregivers working in such settings are often faced with challenges such as dying patients, lack of resources, the risk of being infected and long working hours. The abovementioned factors could contribute to the poor services provided in health care facilities such as Hospices and also could lead to a lack of motivation experienced by caregivers. Caregivers, often operating under overwhelming conditions, could be vulnerable to compassion fatigue, which could eventually lead to secondary traumatic stress and burnout. However, it can also be argued that some caregivers will experience compassion satisfaction when operating under such challenging conditions. This claim will be discussed and supported with evidence in more detail in the analysis and interpretation of the results on the ProQol scale in Chapter 4 (Hudnall Stamm, 2005).

1.2 RATIONALE FOR THE STUDY

The researcher was working as a social worker with terminally ill patients and their families at Family Worship Centre hospice (FWC) in 2004. During that period, the researcher observed the adverse psycho-emotional effect of caregiving on caregivers. The researcher's role at this particular hospice was to offer psychosocial services to terminally ill patients, their families and debriefing services to the caregivers. The researcher observed how reluctant the caregivers became in sharing their emotional experiences when caring for terminally ill patients. However, the debriefing sessions ended up focusing on the caregivers' unhappiness with the working conditions at the hospice as well as low stipends and the lack of medical resources such as gloves and medication to prevent them from being infected with illnesses such as TB.

The researcher became concerned when watching how the caregivers avoided dealing with their emotional challenges when caring for terminally ill patients. The researcher noticed that the caregivers did not feel comfortable in sharing their feelings about the negative impact of their work. Instead they would focus on material issues rather than emotional impact. Some of the caregivers at FWC during the researcher's observations presented symptoms of stress, lack of motivation and fatigue. The researcher therefore developed an interest in exploring the perceived impact of compassion satisfaction, secondary traumatic stress and burnout on caregivers at a hospice caring for terminally ill HIV/AIDS patients. The main objective of this study is to find

out if caregivers were aware of the effects of their work and how their work can have an impact on their personal and professional lives.

Initially the research was meant to be conducted at FWC Hospice as outlined in the proposal. However, due to the small sample of caregivers at FWC Hospice, the researcher approached Sparrow Ministries Hospice which cares for terminally ill HIV/AIDS patients. Sparrow Ministries Hospice had 45 caregivers which were considered a sufficient sample for the purposes of this study. The results and findings of this study are to be shared with both organisations in assisting them to improve the professional support services offered to their caregivers in dealing with compassion fatigue, secondary traumatic stress and burnout.

Sparrow Hospice Ministries was founded in 1992 by Rev Corine McClintock and has since opened its doors to terminally ill HIV/AIDS patients who need palliative care, either referred by the local hospitals and clinics or even by community members. Sparrow Villages, as it is known, it is located in Gauteng province. The hospice offers palliative care to those who are terminally ill as a result of HIV/AIDS and other terminal illnesses. The village can accommodate adults and children in the semi-independent houses. Sparrow Ministries Hospice is a registered NPO relying mainly on funding from government and other private funders. The Hospice has 45 caregivers trained in working with terminally ill patients.

This study tried to provide an insight into how the role of caring for HIV/AIDS patients in a hospice setting could impact on the emotional wellbeing of caregivers. The findings and recommendations of this study will be shared with the management of Sparrow Ministries Hospice with the hope that they will utilise them to improve the psychological support services offered to their caregivers in helping them deal with secondary traumatic stress, compassion fatigue and burnout. Furthermore, the findings are hoped to assist other organisations employing caregivers to provide palliative care services to terminally ill HIV/AIDS patients in ensuring that caregivers are better looked after and as a result can provide better quality palliative care services to the terminally ill HIV/AIDS patients.

1.3 RESEARCH QUESTIONS

The study was underpinned by the following research questions;

- Are the caregivers at Sparrow Ministries Hospice aware of the impact the caring work has on them? What are the levels of compassion satisfaction, secondary traumatic stress and burnout as measured by Hudnall Stamm's (2009) ProQol Scale on caregivers working at Sparrow Ministries Hospice?
- Are caregivers aware of any support services offered to them by hospice? If so, what are those services?

1.4 THE PRIMARY AIM OF THE STUDY

The primary aim is to measure the impact of caring for terminally ill patients on caregivers at Sparrow Ministries Hospice in relation to compassion satisfaction, secondary traumatic stress and burnout.

1.5 SECONDARY OBJECTIVES OF THE STUDY

- To explore how caregivers working at Sparrow Ministries Hospice understand the impact of caring for terminally ill patients has on them. To measure the levels of compassion satisfaction, secondary traumatic and burnout experienced by caregivers working at Sparrow Ministries Hospice using the ProQol scale by Hudnall Stamm (2009).
- To explore the nature of support services offered to caregivers at Sparrow Ministries Hospice in dealing with compassion fatigue, secondary traumatic stress and burnout.

1.6 RESEARCH DESIGN

A detailed description of the research methodology employed by the researcher is presented in Chapter 3. The ethical aspects pertinent to the study and the measures that were taken to ensure

the trustworthiness of the data will also be presented in Chapter 3. The following discussion is a synoptic account of the research methodology adopted for the study.

The study combined both qualitative and quantitative research designs known as a mixed methods design. According to Creswell (2009) mixed methods design focuses on collecting, analysing, and mixing both quantitative and qualitative data in a single study or series of studies. This kind of design combining both approaches provides a better understanding of research problems than either approach alone.

The research population comprised all caregivers employed by Sparrow Ministries Hospice. The researcher made use of a non-probability sampling technique namely availability sampling which requires the researcher to interview participants that are available and willing to participate in the study until such a time as the desired number is obtained and data is saturated (Delport & Strydom, 2011:390).

The researcher made use of one-on-one interviews in order to get in-depth responses from the participants' experiences of compassion satisfaction, secondary traumatic stress and burnout. The questions were open ended to allow the participants to freely share their experiences of their working environment (Bickman, 2009:10). The ProQol scale was utilised to assess the levels of compassion satisfaction, secondary traumatic stress and burnout among caregivers working at Sparrow Ministries Hospice (Stamm, 2009).

1.7 DEFINITIONS OF KEY CONCEPTS

Secondary traumatic stress

Secondary traumatic stress occurs when an individual is exposed to extreme secondary traumatic stress events through interacting with people who have experienced traumatic life events (Jenkins and Baird, 2002).

Burnout

Burnout is associated with feelings of physical exhaustion, negative self-concept, hopelessness and difficulties in dealing with work demands or in doing one's job effectively (Miller, 2000).

Compassion fatigue

Compassion fatigue occurs as a result of the impact of counselling or trauma work on the worker working with trauma victims. Compassion fatigue is also seen as the negative aspect of the work experienced by trauma workers. Compassion fatigue is characterised by issues such as exhaustion, frustration, anger and depression (Figley, 2002).

Compassion satisfaction

Compassion satisfaction is regarded as the pleasure that derives from being able to offer help to someone in need, especially in the workplace. One may feel fulfilled and content through helping others, be it clients or colleagues. Compassion satisfaction refers to the sense of personal fulfilment experienced by people who help others (Hudnall Stamm, 2005).

Caregiving

Caregiving refers to the process of providing care to individuals suffering from an illness, terminal disease or physiological or psychological disorders. In the conceptualisation of caregiving as work, it is considered "something that requires skills that have to be acquired or learned" (Leira, 1994, p. 189).

Palliative care

Palliative care refers to the medical approach aimed at increasing quality of life, prevention of unnecessary suffering and holistic care in relation to patients that often have terminal illnesses but also illnesses that do not possess curative treatment (Birch & Draper, 2008).

1.8 STRUCTURE OF THE RESEARCH REPORT

This report is divided into five chapters. Chapter 1 provides an overall introduction to the main aim and objectives of the study, research questions, definitions of concepts, as well as the methodology applied. Chapter 2 focuses on basing the claims and arguments of the study on literature and previous studies conducted on this topic. It also discusses the three main concepts of this study, namely compassion satisfaction, secondary traumatic stress, and burnout. Caregiving is contextualised within the ecosystems and secondary traumatic stress theoretical

framework. Chapter 3 focuses on the methodology, research design, data collection method and analysis. Chapter 4 presents the findings of both the questionnaire and the ProQol scale using literature presented in Chapter 2 to make arguments and conclude the findings. The main findings and recommendations of the study are presented in Chapter 5. A conclusion on the findings is also outlined in Chapter 5.

CHAPTER TWO

INTRODUCTION

The UNAIDS Report published in 2009 indicated that HIV/AIDS has become a prominent health concern worldwide. The disease does not only affect those diagnosed, but also their loved ones as well as the health care workers who provide their care. South Africa has been declared one of the countries with the highest rates of HIV infections in the world (UNAIDS, 2009). The disease has not only had negative impact on the people diagnosed with HIV/AIDS and their families, but on the health care system as a whole.

According to Van Dyk (2008), as HIV/AIDS treatment became more accessible in South Africa, caregivers and health care workers were faced with more challenges beyond just treating the illness. There was a huge demand for the provision of health care services to people living with HIV/AIDS. The health care sector in this country has been mostly affected by the increasing number of people needing treatment. A number of NPOs got involved by offering other relevant services to ease up the public health systems. Services offered by NPOs include palliative care, home-based care and hospice care. Most NPOs employ caregivers to provide care for people living with HIV/AIDS. Although HIV/AIDS is often regarded as a predominant health challenge in South Africa, there are other terminal diseases such as cancer which require palliative care services such as the kind of services that hospice provides (White & Morton, 2005).

There are inherent challenges and job stresses in caring for terminally ill patients. Caregivers not only provide care to the terminally ill, but also have to deal with human suffering and the death of patients (Miller, 2000). The HIV/AIDS pandemic in South Africa creates additional challenges for health workers and caregivers. Apart from the fact that there is still no cure for the disease, caregivers have to deal with the fear of being infected themselves, losing patients, watching the progression of patients' illness and providing comfort to the patient`s family and loved ones. Caregivers are also exposed to feelings of sadness and they are constantly exhausted while at work. They need support and care in order to provide compassionate care to patients living with HIV/AIDS. The lack of emotional support for caregivers might lead to them running

the risk of suffering from compassion fatigue, secondary traumatic stress and burnout (Uys & Cameron, 2004).

The following chapter aims to discuss the literature of burnout, secondary traumatic stress, and compassion satisfaction as experienced by caregivers. The discussion's point of departure focuses firstly on defining the three main concepts of this study i.e. compassion satisfaction, secondary traumatic stress, burnout and other related concepts. The emotional, psychological and social impact of HIV/AIDS care on caregivers are also discussed, looking at the caregiver's coping mechanisms. The chapter also focuses on exploring the coping mechanisms used by caregivers in dealing with compassion fatigue, secondary traumatic stress and burnout. The challenges of providing hospice care to terminally ill HIV/AIDS patients experienced by caregivers are discussed. Finally, in assessing care for the caregivers, the available support services offered to caregivers in coping with compassion fatigue, secondary traumatic stress and burnout are reviewed.

In order to have a comprehensive understanding of the impact of compassion fatigue, secondary traumatic stress and burnout on caregivers at Sparrow Ministries Hospice, the secondary trauma perspective, which focuses on the secondary exposure to trauma rather than primary exposure was utilised. The secondary trauma perspective deals with the how having been exposed to patients' traumatic life events might have an impact on caregivers caring for terminally ill HIV/AIDS patients (Figley, 1995).

2.1 DISTINCTION BETWEEN SECONDARY TRAUMATIC STRESS, COMPASSION SATISFACTION AND BURNOUT

In order to understand the impact of secondary traumatic stress, compassion satisfaction and burnout on caregivers caring for patients infected with HIV/AIDS, it is important to first understand the distinction between the mentioned concepts. According to Figley (1995), it is easy to confuse the terms since their symptoms and causes are more likely to be similar. Different theorists have argued that these concepts all may refer to the same phenomenon and the distinction could be on whether the impact is negative or positive on the caregiver.

2.1.1 SECONDARY TRAUMATIC STRESS

Secondary traumatic stress is about the secondary exposure of another person's traumatic life events. This kind of stress can also be viewed as the negative experiences deriving from constantly being exposed to other people's traumatic events or listening to their traumatic stories in the line of work (Stamm, 2009). Secondary traumatic stress can be viewed as the kind of stress as a result of helping a traumatised person where the traumatic experience is not direct but indirect. This means the stress that a caregiver working with terminally ill patients who have experienced trauma through the severity of their terminal illness might experience from listening to such traumatic life stories. The caregiver's traumatic experience in this regard is therefore defined as secondary traumatic stress (Figley, 1995).

According to Gwandure (2009), secondary traumatic stress is more psychological than physical and is associated with feelings of helplessness and anxiety, and it is overwhelming. Caregivers caring for terminally ill patients may feel overwhelmed and helpless through watching the progression of the patient's illness. This experience of trauma by the caregiver is regarded as indirect trauma exposure which may lead to secondary traumatic stress. Hudnall Stamm (2009) argues that secondary traumatic stress is a component of compassion fatigue.

2.1.2 COMPASSION FATIGUE

Compassion fatigue occurs as a result of the impact of counselling or trauma work on the worker working with trauma victims. Compassion fatigue is characterised by issues such as exhaustion, frustration, anger and depression. People in the helping field are more likely to experience compassion fatigue as it forms part of their caring tasks. Caregivers become so involved with the work of helping others that in the end they often compromise their own wellbeing. The impact of compassion fatigue on caregivers' experience could be emotional or physical, which is discussed in more detail when focusing on the symptoms of compassion fatigue and other related concepts later on in the chapter (Miller, 2002).

Figley (2007) went further in defining compassion fatigue as an act of being compassionate towards others by bearing their suffering on their behalf. Compassion fatigue can also be referred

to as the negative approach of caring for others as it sometimes has implications of caregivers being preoccupied with traumatised individuals.

The concept of secondary traumatic stress is usually used as a synonym for the term compassion fatigue. According to Stamm (2005), the caregiver's experiences of trauma are not primary but rather secondary and through these secondary experiences, the symptoms of compassion fatigue will arise. The caregiving work can also be seen as emotionally, psychologically and physiologically taxing to caregivers. According to Wright (2004), caregiving is associated with the sense of compassion which in most cases is the motivation for some caregivers to take on the role. However, as positive as it sounds, it is the same caring role that could result in a negative impact on the caregiver's emotional wellbeing. This is what is referred to as compassion fatigue by most authors.

Killian (2008) assessed some of the factors that could lead to the caregiver's vulnerability to compassion fatigue such as being empathic towards their patients by being able to notice the pain of others; having a history of traumatic events; having their own unresolved trauma experiences; assisting with vulnerable groups such as children; and also having high workload which in most cases is associated with a stressful working environment.

Studies have shown that professionals and non-professionals who struggle to keep a professional emotional distance with their patients, eventually suffered from compassion fatigue (Sims & Moss, 1999). Compassion fatigue could also be used as a coping mechanism by some caregivers in order to distance themselves from the stressful working experiences. This kind of a defence can also create a sense of depersonalisation and cynicism. Maslach (2001) argues that within the caregiving role, this could lead to the caregiver withdrawing and creating damage to their role of caring for patients. Through such experiences, the caregiver could start experiencing burnout.

2.1.3 COMPASSION SATISFACTION

Compassion satisfaction is regarded as the pleasure that derives from being able to offer help to someone in need, especially in the workplace. One may feel fulfilled and content through helping others, be it clients or colleagues. Compassion satisfaction refers to the sense of personal

fulfilment experienced by people who help others (Hudnall Stamm, 2005). This may derive from the pleasure of being able to do one's work and helping others.

According to Figley (2007), compassion satisfaction could be reinforced in the workplace through support given to the caregiver, and positive feedback received by the caregiver. The balance between the positive support for the caregiver with the negative aspects of the role, could lead to caregivers playing a more competent and caring role (Cohen, 2002).

Compassion satisfaction could be applied to minimise the effects and negative aspects caused by compassion fatigue. Caregivers often need to feel a sense of accomplishment which as a result will sustain them through any negative experiences and built their confidence and motivation to care for others (Radley & Figley, 2007).

2.1.4 BURNOUT

According to Miller (2000), burnout can be defined as a syndrome of physical exhaustion and negative self-concept which leads to negative job attitude and eventually develops into loss of concern or regard for the people the caregiver is caring for. It is also described as emotional exhaustion, depersonalisation and reduced level of personal accomplishments caused by long-term involvement in situations that are emotionally demanding (Gustafsson, 2010).

The UNAIDS (2009) report on managing stress in HIV/AIDS caregivers, described burnout as a 'process' not an 'event'. Caregivers can continue working while they are stressed until they cannot function anymore, resulting in patients being neglected and treated in an uncompassionate manner. The negative feelings could take long to have an effect on the caregiver. Hudnall Stamm (2009) argues that these negative feelings could take place in a slow and steady process which will eventually have a negative impact on the caregiver.

According to Miller (2000), there are three identified components of burnout: emotional/physical exhaustion, depersonalisation, and reduced sense of personal accomplishment.

Emotional exhaustion refers to not having capacity to offer psychological support to others. Offering psychological support involves listening to traumatised people's traumatic experiences. According to Egan (1998), helping others demands that a counsellor's fully intense presence is

given to the process. Clients can at times pick up when a counsellor's presence in the helping relationship is distracted or not of quality. This occurs mostly when people working with traumatised individuals are emotionally and psychologically exhausted. Mcmann & Pearlmann (2002) refer to the physical/emotional exhaustion as the stage whereby the caregiver feels that emotionally they are exhausted and used up to such an extent that they have nothing to offer their patients.

Depersonalisation brings about the psychological distancing of oneself by the caregiver. The caregiver might start treating patients as objects rather than humans. This may also include unfeeling, callous and indifferent attitudes towards patients. Some authors argue that depersonalisation which is characterised by a distanced uncaring attitude towards patients could also be seen as a coping mechanism for the emotionally exhausted caregiver (Miller, 2000). Avoiding personal attachment might be another way caregivers cope with having to deal with the overwhelming feelings of caring for terminally patients.

The caregiver might experience a sense of personal inadequacy where they feel they are not achieving their professional goals. Feelings of low personal accomplishment may also have an immobilising and demotivating effect on the caregivers. This may also include depression and lowered morale. The issue of motive to become a caregiver becomes questionable at this stage for some (Radley & Figley, 2002). However there are other factors associated with burnout which could also contribute to the aspects discussed (Kiedel, 2002).

The issues around remuneration and working hours might also have an impact on the caregivers and their experiences of burnout. As discussed in Chapter 1, most caregivers work for NPOs who predominantly rely on limited funding and donations (Grandal & Perrewe`, 1995). Caregivers are part of families and communities; therefore they also have responsibilities and dependants. Personal relationships are also vital. In other NGO organisations, caregivers work as volunteers with unrealistic working hours. As a result, the hours spent at work could also have an impact on personal relationships leaving caregivers and their significant others feeling neglected (Kiedel, 2002).

According to Kiedel (2002), there are numerous factors which are associated with burnout. Literature on caregivers has shown that there is a strong relationship between the caregiver‘s age

and the level of burnout experienced (Kidel, 2002)**.** In a study conducted on a group of caregivers in Sweden in 2010 by Gustafsson, Erikson, Strandberg and Norberg (2010), it was discovered than caregivers aged between 19 and 25 compared to those between 35 and 45 showed a high prevalence of burnout. Age and experience have also been found to be positively correlated in the experience and impact of burnout.

Gender was also discussed by Munch (2007) where women were seen to be more at risk of burnout compared to men. It could also be argued that most women are open about their feelings and experiences, while men might prefer internalise their feelings, possibly as a coping mechanism.

Kiedel (2002) argued that there are strong relations between burnout and a person's personality type. People with low self-esteem and confidence issues are seen to be most vulnerable to burnout. People who are overly conscientious, perfectionists and too giving are also prone to burnout.

Studies such as this one have shown that most caregivers would have liked to have studied nursing, but some due to financial constraints opted for caregiving. The duties carried out by nurses and those of caregivers are more or less similar. However, the level of training and knowledge distinguishes the two. Some caregivers might end up feeling frustrated as their first career choice was nursing not caregiving. Unmet career expectations in most case may lead to caregivers feeling stuck and frustrated. As a result, not having joy and fulfilment from their role as caregivers could lead to burnout Wright (2004).

According to Bailey (1995), burnout occurs at a very slow and steady pace and in different stages. The four stages of burnout identified are, enthusiasm, stagnation, frustration and apathy.

Enthusiasm occurs when the professional or caregiver has a tendency to be overly available and to have unrealistic and high hopes and expectations about the job. The level of energy and eagerness to achieve goals at this stage is very high. This usually occurs in the first year on the job (Rotter, 2002).

Stagnation refers to failure to develop progress or advance in one's duties or responsibilities (Bailey, 1995). During this stage the energy levels are slowing down, motivation is decreased

and the priorities and goals are no longer pursued with enthusiasm. At this stage the caregiver can start experiencing disappointment about the job. A lot of negative feelings and perceptions of self are associated with this stage. The caregiver can be seen as starting to be more interested in fulfilment outside the job, such as being with friends and taking part in sport rather than the actual job responsibilities. Self-doubt becomes a dominating factor and questions around being in the right job are also asked at this phase. The caregiving role can be very demanding under any circumstances, but if one has self-doubt and has little faith, the consequences might be overwhelming and dire (Maslach, 2000).

As the difficulties seem to multiply, the helper becomes frustrated, bored, less sympathetic and might start coping by avoiding and withdrawing from relationships. The caregiver might feel frustrated and torn between sacrificing their own needs to fulfil those of the clients. Should this process be prolonged, the caregiver might move on to apathy (Bailey, 1995).

As the difficulties seem to multiply, the helper becomes frustrated, bored, less sympathetic and might start coping by avoiding and withdrawing from relationships. The caregiver might feel frustrated and torn between sacrificing their own needs to fulfil those of the clients. Should this process be prolonged, the caregiver might move on to apathy (Munch, 2007).

Apathy is seen as the final most dangerous stage as it is sometimes characterised by depression. At this stage the caregiver takes the job as a job, but does not pay any special attention to the patients. The caregiver might start presenting with a more negative attitude associated with complaints and bickering. During this final stage of burnout, the caregiver might not be seen as functioning to their best ability. In the end the relationship between the patient and caregiver might be compromised (Wright, 2007).

2.2 SYMPTOMS OF COMPASSION FATIGUE, SECONDARY TRAUMATIC STRESS AND BURNOUT

Figley (2007) defined the physical symptoms as most common and can be identified easily. Among others these may include headaches, physical exhaustion, sleeplessness, gastrointestinal disturbances and malaise. The immune system might also be affected which then makes one

vulnerable to illnesses such as flu and colds. The physical symptoms are therefore linked to a high rate of absenteeism from work.

A person experiencing the physical symptoms might be easily irritated and prone to anger. The caregiver can also start self-distracting by abusing alcohol and drugs. Interpersonal relationships are also affected and the person may start isolating themselves from other people. In a working environment the person might also isolate themselves from colleagues. This can also affect their problem solving abilities and lead to impulsiveness and acting out. Absenteeism then becomes a huge challenge as the caregiver would start avoiding being at work and around others (Collin & Longa, 2003).

The emotional symptoms may be identified when a person might start feeling helpless, trapped, defeated and detached. This experience also involves a sense of failure and self-doubt where a person does not feel a sense of accomplishment and worth. In most cases a person can also start feeling lonely even when around people, especially at work. There is an increase in a cynical and negative attitude towards oneself (Bailey, 1995).

Secondary traumatic stress has slightly different symptoms from burnout as it is as the result of the traumatic experiences of those traumatised individuals we help. Caregivers experiencing secondary traumatic stress may start having nightmares and difficulties in sleeping. The impact of the secondary traumatic experiences may lead to the caregiver avoiding situations or places that will remind them of the event. The caregiver might also start developing fear and may not function properly, which will affect their relationships with fellow caregivers. Aggression towards others might also develop, which might eventually lead to absenteeism as the aggression towards others becomes very strong (Figley, 1995).

Compassion satisfaction on the other hand presents with more positive feelings and as a result the symptoms are more positive. According to Hudnall Stamm (2009) a person experiencing compassion satisfaction from their work, feels a sense of pleasure in helping others. Relationships with colleagues and clients are more positive. Caregivers with high levels of compassion satisfaction may be seen to have greater satisfaction about their work and contribution to society.

The following sections focus on discussing how secondary traumatic stress, compassion fatigue and burnout impact on caregivers' work. The discussion involves focusing on the setting were caregivers are mostly employed. For the purposes of this study hospice care was the selected setting as the participants in the study are employed at a hospice. The kinds of services rendered by the hospice and the role of caregivers are also discussed, with HIV/AIDS terminally ill patients as a focus.

2.3 HOSPICE CARE

Hospice was introduced as a service rendered to terminally ill patients. The main aim of hospice care is to improve the quality of life of terminally ill patients by removing or controlling the unpleasant pain during the last stages of the illness (Sims & Cameron, 2004). Palliative care is a service provided to terminally ill patients at hospice. With more and more people being infected with HIV/AIDS, palliative care became a crucial service offered to terminally ill patients. According to Whiteside & Sunter (2000), palliative care is used to control and manage the pain during the last stages of the illness also referred to as end of life.

Terminally ill patients in the last stages of the illness need to be in an environment that is comfortable. Hospice provides them with a homely living setting where they are surrounded by people who care for them. Patients are also given an opportunity to deal with the fear of death and dying in the privacy of their own space. Continuous care and support are offered to patients on a daily basis. Pain management and control is also a priority for hospice care for terminally ill patients. Bereavement counselling, support and follow-up is offered to the patient`s family during this difficult time (Sims & Cameron, 2004).

In South Africa, hospice has become a valuable service not only to cancer patients but also to patients with other illnesses. The increase in people living with HIV/AIDS in South Africa has led to more NGOs assisting the public health care system by offering palliative care to such patients (Zimmerman, 2001). However, although there is still no cure for HIV/AIDS it does not mean that people diagnosed with the illness automatically will die. Most patients who are admitted to a hospice with a CD4 count of less than 300 have been seen to be improving and discharged back into their families. The reason for some of the patients reaching that stage might

be due to defaulting on the treatment therefore developing resistance to the antiretroviral drugs (Swanepoel & Louw, 2010).

2.4 THE CHALLENGES WITH HOSPICE CARE

As much as hospice care can be viewed as a good environment for terminally ill patients, some patients find it too painful as it signifies the end of life for them. The fear of death and dying does not only affect the patient but the people caring for him or her. The carers could be family members, close friends, a spouse, health care professionals and caregivers (Kubler Ross, 1997). Helping the patient deal with such challenges may have negative impact on the caregiver. Issues of death and dying are not always easy to handle as they also involve fear of the unknown.

Hospices have mostly been run by NPOs who rely on private funders and donations. There are sometimes issues with lack of funding which leads to inadequate resources for the hospice to cope with the demands. The issue of insufficient medical items such as gloves, medication to prevent infections, and painkillers, at times places a lot of pressures on caregivers. The medical supply is also meant for caregivers to prevent them from infections such as Tuberculosis (TB) from patients who have developed Multi Drug Resistance (MDR). Caregivers in most cases feel underqualified and undertrained to cope with the demands of the job and the illness. The UNAIDS (2010) report shows that South Africa `s HIV epidemic is one of the worst in the world and has not shown enough evidence of declining. This places a lot of strain on the health care system and already gives a picture of the future of caregivers in this country.

2.5 ROLES AND RESPONSIBILITIES OF CAREGIVERS IN HOSPICE CARE

According to Munch (2007), caregivers in hospice care are required to respond to the patients' physical, emotional and spiritual needs.

During the last stages of the illness most patients lose their mobility, which requires caregivers to do things for them. This includes bathing, dressing, feeding and moving the patients around. It is a very sensitive issue for most patients as it involves loss of control of one`s own life. It is could

also be a challenge for caregivers as it puts them under risk of contracting diseases and also of having to deal with difficult patients (Wright, 2004).

The caregiver's role involves interacting with patients on a day to day basis. The interaction gives the caregiver a role of a listener as they pay attention to the patient`s emotional needs. This, however, requires proper training on the caregiver`s part to avoid imposing feelings of inappropriate guilt on the patients. It is also to protect the caregiver from suffering from compassion fatigue. The final stage of the illness is characterised by feelings of fear around death and dying which requires that the caregiver be fully equipped to respond to those demands (Van Dyk, 2008). This is when supervision and debriefing become crucial in the life of a caregiver.

According to Munch (2007) in the article "Letting go, society for the promotion of Christian knowledge", argues that in the last stages of the illness, patients start seeking the meaning of life. The first area in their life that gets assessed is the spirituality and religion. It is important during this time for caregivers to respect the patient`s beliefs and not impose their own. Patients may experience a need for forgiveness of themselves, others and God. This role should be outsourced to chaplains and religious ministers the patient chooses. This would therefore assist in alleviating the pressure on caregivers and deal with the issue of role confusion as discussed earlier.

This study focused on caregivers working at a hospice with terminally ill HIV/AIDS patients. The challenges and impact of caring for terminally ill HIV/AIDS patients are discussed next.

2.6 THE IMPACT OF CARING FOR TERMINALLY ILL HIV/AIDS PATIENTS ON CAREGIVERS

South Africa's HIV/AIDS epidemic has had a devastating effect on people infected and those living with them (UNAIDS 2010). HIV/AIDS comes with stigma attached. As much as people infected do not want to disclose their status due to the fear of being stigmatised, caregivers working in the field are also afraid of being associated with the disease. It is sometimes difficult to even walk in the community as a caregiver without people pointing at them because they were seen going into a family where there is a person dying of AIDS. HIV/AIDS work itself is in some situations a stigmatised activity, by mere association with HIV-infected people (Russel and Schneider, 2000).

HIV has a significant impact on the people who disclose to the person who has been diagnosed. Families, friends and partners may experience a range of emotional reactions including fear, anticipatory grief, shame and helplessness, which can impede coping and create disruptions and relationship problems. They may also be struggling against real or perceived discrimination within their communities and even within their families. Family members, friends and partners who are HIV positive themselves may face additional challenges. A study conducted by Skhosana (2001) on women, HIV/AIDS Stigma , An Anthropological study of life in a hospice, the findings showed that people living with HIV/AIDS and their families are still experiencing stigma from community members.

Individuals affected by HIV may be influenced by psychological stressors common to other chronic or life-threatening illnesses, such as cancer or heart disease. These challenges include dealing with loss, fear of illness and death, perceived helplessness, uncertainty about the future, anxiety, sadness, anger, anticipatory grief, and frustration in navigating in the medical system, financial worries, and interpersonal stress (Higgings & Norton, 2010).

According to Walker (2001), how a family copes with any illness, including HIV depends on the nature of the family organisation and the belief systems that govern the family's response to the illness. The impact on the family also varies with their ethnicity, religion, race and social class, the family's developmental level, and the family's relationship with the treatment providers. As discussed earlier in the chapter, coping can be regarded as an individualised process that cannot be generalised.

The study focused on measuring the levels of compassion satisfaction, secondary traumatic stress and burnout experienced by caregivers at Sparrow Ministries Hospice. The three concepts have been defined and their symptoms discussed in more detail. This chapter tried to understand the abovementioned impact by discussing the setting in which the caregivers operate. The caregivers who participated in this study work in a hospice setting with terminally ill HIV/AIDS patients. The coping strategies in dealing with secondary traumatic stress and burnout are discussed next.

2.7 CAREGIVERS' COPING STRATEGIES IN DEALING WITH SECONDARY TRAUMATIC STRESS, COMPASSION FATIGUE AND BURNOUT

According to Munch (2007), coping refers to the implementation of certain behaviours internally in response to difficult situations. Coping is an individualised and contextualised activity which can never be generalised. Different people deal with and manage stressful situations in different ways regardless of whether they experience the same traumatic event or not. As discussed earlier, issues of age, gender and marital status could be seen to have an impact on how the caregiver experiences secondary traumatic stress and burnout (Wright, 2004).

There are two methods identified for coping with burnout and secondary traumatic stress. The first is the direct approach which involves the individual taking charge of the situation and trying to change what she or he can. The second one is a more indirect approach whereby the individual accepts and adapts to what they cannot change or control. In other words coping with burnout and secondary traumatic stress depends entirely on which approach the individual caregiver adopts (Kiedel, 2002).

In discussing the caregivers' coping mechanisms in dealing with compassion fatigue, secondary traumatic stress and burnout, one can use the social work perspective which focuses on three levels in order to bring about change (Dominelli, 2004). The levels are the micro-level which deals with interpersonal relations, the meso-level which looks more at legislation, institutions and policies and finally the macro-level which focuses more on the entire environment.

2.7.1 PERSONAL COPING STRATEGIES

The personal coping strategies involve maintaining a balance between personal and professional life through clarifying whose needs are being met (Joslyn, 2002). The caregiver could also conduct an honest self-evaluation and assessment of the workplace by setting goals and boundaries. However, this exercise might be difficult for some as caregiving was not their first career option as discussed earlier in the chapter (Uys & Cameron, 2004). It is necessary for the caregiver to monitor tendencies to get overinvolved by addressing issues from the patient's and family's perspective rather than being personally too involved. The caregiver may also establish

good communication skills with people involved in their work and the ability to express their feelings. Effective coping is facilitated by the use of good communication skills (Kiedel, 2002).

On a more practical level, the caregiver might need to cultivate a supportive and enjoyable social network through striving for balance in family and professional life (Wright, 2002). People living alone have been seen to be more vulnerable to experiencing secondary traumatic stress and burnout. The reason might be that having social networks and being able to share the stress with people who are close might reduce the level of stress experienced at work (Wright, 2004). Combating stress might also require that the caregiver assess their lifestyle by eating healthily and getting adequate sleep and exercise. Taking leave when needed and having a standby relief might give the caregiver an opportunity to rest (Skovholt, 2001).

2.7.2 PROFESSIONAL COPING STRATEGIES

Counselling can be referred to as a service that is rendered to address emotional and psychological needs. Counselling helps in maintaining quality of care and positive outlooks when charged with another's care. Counselling also enhances the caregiver's ability to reclaim their emotional lives and function properly (Thompson, 2003). Caregivers are in a unique position to provide care for other people's needs. It is therefore crucial that the caregivers also take good care of themselves. Caregiving is a mentally and physically demanding task and often takes its toll on the caregivers. Counselling should therefore be utilised to assist caregivers with emotional support so that they can be able to handle difficult situations and help others effectively (Clark, 2011).

Debriefing can be referred to as a crisis intervention method with an individual who has experienced a stressful or traumatic event (Liliefeld, 2007). A crisis or trauma is said to occur when the individual's usual coping and problem-solving methods fail to resolve the situation. In addition, the event is perceived as a threat to the client. Debriefing therefore aims at cushioning the emotional impact of the event, to strengthen the client's coping efforts and to restore the client's pre-crisis level of functioning. It is critical that any trauma worker prioritises their emotional wellbeing. To successfully work in an emotionally demanding setting, one must have an understanding of the consequences of that work. It is also important for caregivers not to

detach themselves, in order to provide the best, most compassionate care for others (Lesser & Pope, 2007).

According to Wright (2004) organisations need to support their caregivers in dealing with emotionally demanding situations. Debriefing could therefore be used as an intervention strategy to assist caregivers to deal with their feelings, thoughts and experiences in caring for people living with HIV/AIDS. This could be conducted by a qualified professional in individual sessions or in a group.

According to Figley (1995), the cost of recruiting, hiring and training new staff is significant. Burnout is a contributing factor towards turnover. Turnover brings down staff morale, increases workload for remaining staff, results in poor continuity of care for the clients and prevents organisations forming a high functioning and cohesive workforce (Munch, 2007). In addition, the quality and quantity of a staff member's work may suffer if they have been secondarily traumatised and do not receive assistance. It is therefore crucial for organisations employing caregivers to acknowledge the cost of caring on caregivers and implementing professional services to assist caregivers in dealing with secondary traumatic stress and burnout.

2.7.3 ORGANISATIONAL SUPPORT

Hesse (2002) suggested that in order for organisations to be able to assist caregivers in preventing and dealing with burnout, supervision and support groups need to be put in place on an organisational level.

According to Brown & Bourne (2002), supervision can be defined as the dynamic interaction between supervisor and supervisee in an individual or group context. The overall aim of supervision is to provide a qualitative service in accordance with the needs of the client, ethics of the profession, and policies of the particular organisation. There are five functions of supervision, namely education/training, administration, motivation, support and modelling (Kadushin, 2002). For the purposes of this study the researcher will focus on the supportive function of supervision.

The supportive function of supervision focuses on dealing with stress and emotional factors that impact negatively on the efficiency of workers. The most valuable assets for any organisation are the workers. The nature of work in the helping professions places high demands on workers' physical, emotional and psychological wellbeing. Workers in the helping professions need an opportunity to process the impact their work might have on them in order to prevent burnout and to be able to stay resourceful to provide effective services (Zastrow, 2012).

Support groups are also recommended as a way of debriefing the caregivers and encouraging support among themselves. Support groups offer a safe environment to caregivers in order to share their experiences and, most importantly, to support each other. The support groups can also be in the form of peer groups, not necessarily therapeutic groups. Peer groups are less formal and can allow caregivers a chance to be free and share their challenges while helping each other cope with the work demands. In most cases a group leader is chosen with peers and they form a group where issues are discussed and ideas are shared on how to cope with work demands (Wright, 2004).

2.8.4 Organisational structural factors

According to Stein (2000), the physical working conditions of the organisation, the management policies and the incentives paid to the employees have an impact in what is referred to as job satisfaction. Included in the above mentioned factors could be working hours, time off, workload and the nature of the work tasks. It is therefore crucial for organisations employing caregivers to address such organisational structural factors in helping their employees cope with the impact of caring for terminally ill patients.

Organisations that develop good strategies to assist caregivers cope with the demands and challenges of their work will prevent issues of staff turnover. Training and recruiting new staff members can be costly and also prevents organisations from forming a high functioning and cohesive workforce. Staff turnover brings down staff morale, increases workload for the remaining staff resulting in poor continuity of care for patients (Ordman, 2001). Based on the findings and experiences of some researchers in this field, organisational prevention strategies assist in the increasing of caregiver's wellbeing and compassion satisfaction. Such strategies also reduce the risk of caregivers suffering from secondary trauma, compassion fatigue and burnout.

2.8 CONCLUSION

According to Van Dyk (2008), a caregiver could be anyone involved in caring for the physical, emotional and psychological needs of a person living with HIV/AIDS. Caregivers are exposed to feelings of sadness and constantly feel exhausted. They may need support and care to deal secondary traumatic stress, compassion fatigue and burnout. Van Dyk (2008) conducted a study at UNISA with 243 caregivers who were about to start a course on HIV/AIDS counselling. The focus of the study was on what stress factors affect health care workers involved in HIV/AIDS work and care, the symptoms, services offered by employers as support services and also their own coping mechanisms.

In her findings, Van Dyk (2008) reported the following recurring themes from the findings of the study: caregivers battle with bereavement, they over identify with the patients, they suffer from fear of being infected with HIV in the workplace, they feel inadequately trained and prepared for the job, they felt unsupported by the employers and finally there is anger towards the government on the slow release of antiretroviral treatment for people living with HIV/AIDS.

It is therefore crucial for organisations employing caregivers to care for terminally ill patients to develop strategies in helping them cope with the work demands, and preventing secondary traumatic stress and burnout (Kiedel, 2002).

2.9 THEORETICAL FRAMEWORK

2.9.1 INTRODUCTION

In order to have a comprehensive understanding of the impact of caring for terminally ill patients on caregivers in relation to compassion satisfaction, secondary traumatic stress and burnout, the secondary traumatic stress was used as a theoretical framework.

According to Figley (1995) secondary traumatic stress occurs as a result of trying to help a traumatised or suffering person. The trauma experienced by the caregiver is indirect and secondary as compared to those of the traumatised person. It is also characterised by empathy and the need to rescue those who are suffering. People who chose to work in human service

occupations often feel an edge to sympathise, understand and work selflessly with people who are suffering. Sympathy shown to traumatised persons by caregivers may lead to apathy which then leads to burnout. Secondary traumatic stress is also characterised by negative internal psychological experiences which can be as a result of the working conditions.

2.9.2 SECONDARY TRAUMATIC STRESS A CHALLENGE FOR CAREGIVERS

MacCann and Pearlman (2003) mentioned that working with people that has experienced trauma could disrupt the social functioning of the caregiver. In hospice environment, working with terminally ill patients facing death could be traumatising for caregivers. However as mentioned earlier, the kind of trauma they experience is secondary. Working in an environment such as hospice, caregivers are bound to feel helpless and demotivated especially on the realisation that the patient's condition might not improve.

According to Stein (2000), an imbalance between job demands and available resources could lead to an emotional response characterised by anxiety, tension, fatigue and exhaustion. The end results could lead to negative change in how the individual views their job. The nature of hospice work is characterised by patients who might not get better and die. As a result, caregivers working in such environment including volunteers are faced with constant loss. Working directly with terminally ill patients and their families were identified as the common stressors on caregivers working in hospice. Some of the stressors includes issues such as, patients who are in denial about their condition and stage of the illness, helping family members accept the condition of their oved one, and finally dealing with the death and loss of a patient.

2.9.3 PROFESSIONAL QUALITY OF LIFE AND SECONDARY TRAUMATIC STRESS

As defined earlier in the chapter, secondary traumatic stress involves an indirect exposure to trauma through one‘s involvement with people that have been exposed to traumatic events. There are factors which lead to organisations hiring caregivers to be concerned about secondary traumatic stress and its impact on the caregivers. Some of those factors are economic factors dealing with the cost of recruiting and hiring and training of new staff members. Staff turnover

has been seen as bringing down staff morale, increasing work load for the remaining staff which could result in poor continuity of care for patients with terminal illness. The results of all this would also mean that the organisation could be prevented from forming a high functioning and cohesive workforce. The quality and quantity of the caregiver's work may suffer if they have been exposed to trauma and did not receive professional help (Figley, 1995)

2.9.4 CONCLUSION

Working with terminally ill HIV/AIDS patients in a hospice setting may place caregivers in a vulnerable position for compassion fatigue, secondary traumatic stress and burnout. In South Africa HIV/AIDS has become a health challenge with more people infected and needing hospice care. There is no cure for the illness, which places more strain on the health care system and on caregivers. Coping strategies to assist caregivers deal with compassion fatigue, secondary traumatic stress and burnout become crucial for NGOs employing caregivers. Change efforts are usually directed at reducing challenges that comes from the person's environment demands through increasing support and strengthening the caregiver's coping abilities (Wright, 2004).

According to Stamm (2010), professional quality of life involves both the positive and negative aspects of the helper's work. It is crucial to have a balance as both aspects has a huge impact in how the caregiver performs his or her duties. The negative aspects of the caregiver's work could have an impact not only on their job but also on the people around them. Therefore there is a great need for strategies to assist caregivers deal with the negative aspects of their work and increase compassion satisfaction which is regarded as the positive aspect of one's work. Secondary traumatic stress cannot be avoided in a hospice environment, but can be managed through strategies ensuring better care of caregivers. Caregiver's awareness of the impact of caring for terminally ill could also assist in developing better self-care strategies and increasing compassion satisfaction.

CHAPTER 3

INTRODUCTION

The research conducted focused on measuring the impact of caring for terminally ill patients on caregivers at Sparrow Ministries Hospice in relation to, secondary traumatic stress, compassion satisfaction and burnout. The methods section presented the research questions, as well as a framework in which the interpretation and analysis were conducted. The section also considered the data collection methods and data analysis in more detail. The limitations of the study as well as strategies to overcome them are discussed in this chapter.

3.1 RESEARCH DESIGN

The study was conducted utilising a mixed-methods research design as the study incorporated both qualitative and quantitative aspects. According to Creswell (2009), a mixed methods design focuses on collecting, analysing, and mixing both quantitative and qualitative data in a single study or series of studies. The combination of both approaches provided a better understanding of the research problem than applying either approach alone. The study aimed to explore the level of compassion satisfaction, secondary traumatic stress and burnout among caregivers at Sparrow Ministries Hospice and coping strategies. By combining both approaches, the researcher was able to use multiple data sources which are referred to as triangulation. Triangulation, according to Shaw, Briar-Lawson, Orme & Ruckdeschel (2010), occurs when data from one method is used to corroborate data from a different method, both testing the same phenomenon.

In this study, the Professional Quality of Life scale (ProQol) was used to measure the caregiver's levels of burnout, secondary traumatic stress and compassion satisfaction. The scale was selected for this study as it has been commonly used to measure the positive and negative aspects of working in stressful conditions and with people that have experienced trauma (Stamm, 2010). The scale was developed first in English before been translated into other languages. In this study the participants where second language English speakers. However a pilot study was conducted to assess if the language used on the scale would be understood by the participants. None of the items where changed on the scale as it was shown to be easier for caregivers who

participated in the pilot study to understand. The scale measured three separate constructs namely compassion satisfaction, burnout and secondary traumatic stress. The three scales measured the negative effects of the work in different ways. For example the burnout scale measured the negative effects of caring for traumatised people while the secondary traumatic stress scale focused on measuring the secondary exposure to traumatic events.

The scale was individual administered to the participants and they were allowed to fill in the answers themselves. Each participant was able to complete the scale in 30 minutes. The researcher explained to the participants what they were expected to do in completing the scale. The scale also had instruction for the participants to fully understand how to complete.

A semi-structured interview schedule was administered face to face in order to get in-depth information on the caregivers' experiences of caring for terminally ill patients in relation to compassion satisfaction, secondary traumatic stress and burnout. The interview schedule was made up of 27 questions both closed and open ended. The questions addressed the research aim and objectives focusing on the working experience, coping mechanisms and the support services offered to help deal with the negative effects of work as a caregiver. The participants did not consent to tape recording; therefore the researcher had to make notes while interviewing them. The face to face interviews allowed for both the participants and the researcher to seek clarity on the questions and answers.

3.2 RESEARCH METHODOLOGY

3.2.1 POPULATION AND SAMPLE

The population for this study comprised 45 caregivers working at Sparrow Ministries Hospice providing care to terminally ill HIV/AIDS patients and their families. The caregivers had to have been employed at the hospice for over six months in order to take part in the study. The reason for the six months' employment experience is that caregivers would have experienced the demands of the job and may have experienced secondary trauma as a result of their work.

According to Van Dyk (2008), the more experience the caregivers have in the field of HIV/AIDS the better will be their chances of developing coping mechanisms to deal with secondary traumatic stress, compassion satisfaction and burnout.

3.2.2 SAMPLING PROCEDURE

The researcher was invited to attend one of the staff meetings at the hospice with all the caregivers. The aim was to present the research topic as well as the aims of the study and to invite the caregivers to voluntarily participate in the study. The whole population was invited to voluntarily participate in the study. Out of 45 caregivers, 15 voluntarily gave consent to be part of the study. Consent forms were handed over to the 15 participants to be signed before the actual interviews were conducted.

3.3.3 RESEARCH INSTRUMENTATION

The researcher made use of two research instruments for this study. The first one was Hudnall Stamm's (2009) Professional Quality of Life (ProQol) scale. Secondly, a semi-structured interview schedule was administered face to face to the caregivers.

The ProQol version 5 adopted from Hudnall Stamm (2009) was utilised to measure the levels of compassion satisfaction, secondary traumatic stress and burnout experienced by caregivers at Sparrow Ministries Hospice. The scale was made up of 30 questions with a 1 to 5 choice based on the number that reflected how frequently caregivers experienced the things that were asked on the scale. The questions covered three aspects secondary traumatic stress, compassion satisfaction and burnout.

The semi-structured interview schedule was made up of open-ended questions. The participants were given an opportunity to ask for clarity and the researcher also used the opportunity to probe and ask follow-up questions. As a result the researcher got an in-depth understanding of the caregivers' experiences of burnout, secondary traumatic stress and compassion satisfaction. The semi-structured interview schedule ensured that all participants were asked the same questions during the interviews.

3.3 PILOT STUDY

According to de Vos (2011) pilot testing of the research tool makes sure that errors in the research study could be avoided. A pilot study also allows the researcher to have room for improvement and adjustments before the actual study. The research tool was piloted on five home-based caregivers at Aurum Institute. Aurum Institute focuses on HIV/AIDS and ensuring that people adhere to treatment even in the comfort of their homes. Feedback given by the five caregivers at Aurum Institute was utilised to make adjustments to the questions that were not clear to the participants before the actual study was conducted. The adjustments were only on the questionnaire, not on the ProQol scale. Some of the questions were not clear during the pilot study interviews. The researcher had to take into consideration that none of the participants were English first language speakers. Therefore the questions on the semi-structured interview schedule had to be adjusted to address the second language issue. Using social work skills such as probing, immediacy and summarising, the researcher tried to make sure that the participants were able to answer the questions. The sample used in the pilot study did not form part of the actual sample of the study.

3.3.1 DATA COLLECTION

The researcher conducted face-to-face semi-structured interviews to obtain rich information on the experiences of burnout, secondary traumatic stress and compassion satisfaction as experienced by the caregivers at Sparrow Ministries Hospice. This gave both the researcher and the participants an opportunity to clarify issues, to probe and to ask questions where necessary. Initially the researcher intended to use a tape recorder to capture the true interpretation of the responses.

None of the participants gave consent for their responses to be tape-recorded. As it was mentioned in the participant information sheet that the tape recorder was not compulsory, the researcher had to respect the wishes of the participants. The researcher was aware of the lack of trust in management by the caregivers from the start. This was attributed by their first lack of interest in being part of the study and how reluctant they were. The kind of remarks made during the recruitment phase of the research indicated to the researcher that there might be issues of

trust amongst the caregivers towards the hospice management. The researcher therefore had to rely on the notes taken during the interviews where direct quotations were recorded in order to analyse the data. The issue of how accurate did the researcher capture the participants' answers could be seen as a limitation to the findings of this study which is discussed later on.

The data collection method used in this study was triangulation whereby both qualitative and quantitative designs were used to collect data. Triangulation allows the researcher an opportunity to use more than one data collection method to analyse the same information (Rubbin & Babbie, 2005). In this study the researcher also used the Hudnall Stamm (2009) ProQol scale to measure the levels of compassion satisfaction, secondary traumatic stress and burnout on caregivers at Sparrow Ministries Hospice. The scale was administered individually in a private room by the researcher. As an ice breaker, the scale was administered first before the interviews to make the participants feel at ease. The scale was self-administered with the assistance of the researcher were clarity was needed. The researcher was careful not to influence the answers by explaining the instructions before the test was taken and leaving it up to the participants to complete. The scale was in English and the participants were second language speakers. However during the pilot study the researcher did not find any difficulties with language issues. The caregivers had some level of education as a requirement by the hospice policy in order to complete the courses offered. As a result none of the items on the scale were edited for language issues only on the interview schedule. The interview schedule needed caregivers to understand the questions clearly in order to share their experiences of caring for terminally ill patients.

3.3.2 DATA ANALYSIS

In analysing mixed-methods research, the researcher combined both strategies of qualitative and quantitative data analysis methods. The researcher made use of Thematic Content Analysis and descriptive statistics to analyse the collected data. The two data analysis methods used incorporated both qualitative and quantitative data analysis method sine the study utilised mixed methods design.

3.3.3 THEMATIC CONTENT ANALYSIS (TCA)

The interviews were not tape-recorded but instead the answers were typed and then analysed using TCA. Babbie & Mouton (2001) talk about a process in qualitative of data analysis which focuses on recurring themes and frequency of comments. TCA was used to identify the themes and frequencies of comments resulting from the participants' responses in the interviews. According to Terre Blanche & Durrheim (2006), there are five steps in undertaking Thematic Content Analysis. Firstly the researchers needed to familiarise themselves with the data, secondly, look for common themes recurring, thirdly, assign codes to the themes identified, fourthly, elaborate on the themes in a more in-depth manner, and finally, using literature as outlined in Chapter 2, analyse and interpret the meaning of the themes identified.

3.3.4 DESCRIPTIVE STATISTICS

In analysing the ProQol scale results, the researcher added the scores of all three components i.e. compassion satisfaction, secondary traumatic stress and burnout and analysed them individually and then in groups. The test scores were used to interpret and analyse the levels of compassion satisfaction, secondary traumatic stress and burnout as scored by caregivers. The data were presented using graphs and tables. Descriptive statistics were used to analyse the quantitative data by utilising graphs and diagrams to present the calculated scores from the ProQol scale (ProQol Manual, 2009).

3.4 RELIABILITY AND VALIDITY

3.4.1 RELIABILITY

According to Neumann (2007) reliability refers to the dependability and consistency of the results when a particular technique is applied repeatedly to the same object. It is also about if whether the instruments administered to the same population but not at the same time would have the same results. The idea is to find out if the results and findings would be consistent and that the instrument was reliable. The study made use of the ProQol scale with three subscales

measuring secondary traumatic stress, compassion satisfaction and burnout in separate forms. An interview schedule with open ended questions was also used to collect data. The two instruments were administered to the same population individually at different times. The questions on both instruments were the same. However, participants had different answers depending on their experience of the three constructs and their understanding of how the work impact on them.

. A semi-structured interview schedule was also administered face to face to the participants. The open-ended questions on the schedule focused more on asking the participants about their experiences of the three components measured by the ProQol scale in more detail.

3.4.2 VALIDITY

Validity focuses on checking and ensuring whether the results of the test adequately reflect the true meaning of the concepts being measured in the study (Rubin & Babbie, 2005). It is also argued that a test can never adequately reflect the true meaning of the concept under questioning. Face validity therefore focuses on looking at several reasons why the test result can never reflect a true meaning of the concept being tested. There are several reasons for such a claim; firstly the number of participants who took the test should be taken into consideration. A small sample might make it difficult to ensure that the test results could even be close to reflecting the true meaning of the concept tested. This study comprised only 15 caregivers employed at Sparrow Ministries Hospice which was a small proportion of the whole population of 45. The kind of people taking part in the study might also have an impact on the test scores based on the kind of work they do and the questions the scale asks in relation to their work (Rubin & Babbie, 2005).

The ProQOL has been administered for years on people working with traumatised people. There are three scales measuring negative aspects of the work but in different ways. For example the burnout scale focuses on measuring the negative aspects of the work which brings about negative feelings. The secondary traumatic stress scale focuses on the secondary exposure to the traumatic events. However the scales both are seen to be measuring what is referred to as the negative effects of caring for traumatised people.

The three scales in this study measured different concepts: compassion satisfaction, secondary traumatic stress and burnout. Compassion satisfaction focuses on the pleasure derived from performing well in one's job. Secondary traumatic stress on the other hand refers to the stress derived from helping individuals that have experienced trauma. Burnout therefore is regarded as the negative feelings associated with unbearable overtime experiences at work (Stamm, 2009). One can therefore argue that the true meaning of the three concepts might not be adequately reflected in the results of the ProQol scale. As mentioned earlier some of the questions on the scale asked questions that challenged the caregivers to assess how they feel about their work. Some of the caregivers' answers might have been what they thought the researcher wanted to hear. However, some of the items on the scale had to be reversed to ensure that high or low scoring on such items is adequately reported.

3.4.3 CONFORMABILITY

Miles and Huberman (1994:34) contend that "detailed methodological descriptions enable readers to determine how far the data and constructs emerging from it may be accepted." To ensure conformability the researcher made use of direct quotations from the respondent experiences. By so doing, the researcher tried to ensure that the research findings are a result of the experiences of the respondents, rather than the views of the researcher (Schurink, Fouchè & De Vos, 2011).

3.4.4 TRANSFERABILITY

To ensure transferability the researcher made use of the secondary traumatic stress perspective. The same study if conducted under the same parameters might produce the same results as the study. However the results in this study cannot be generalised due to the following: sample size, geographical location of the organisation and organisational structures that participated in the study (Schurink, Fouchè & De Vos, 2011).

3.4.5 CREDIBILITY

Miles and Huberman (1994:34) recognise the importance of correct operational measures for the concepts being studied and the need for specific procedures to be employed, such as the line of questioning pursued in the data-gathering sessions (Schurink, Fouchè & De Vos, and 2011:386). The researcher made use of the ProQol scale and a semi-structured interview schedule which ensured that all participants received the same questions.

3.5 ETHICAL CONSIDERATIONS

The following ethical considerations were applied by the researcher throughout the study:

- The researcher respected the participants' decision not to participate in the study. Therefore none of the caregivers at the hospice were forced to become part of the study.
- An informed consent form was given to participants so that they could volunteer to be part of the study or not, with the understanding that there would be no negative consequences reflecting on their job should they choose not to participate in the study.
- The collected data remained confidential until the study was completed and the findings will be presented to both the organisations and to the participants. A written thesis report was submitted to the faculty of humanities at the University of the Witwatersrand.
- Information revealed by caregivers about their patients was also kept confidential and no names of those patients were used in the study, to protect their rights to privacy.
- The study might have evoked traumatic experiences for some of the caregivers. The participants were notified in the beginning that they would be referred for professional trauma counselling if it were needed, free of charge. None of the participants needed to be referred for counselling during the study.
- Permission from management by whom the caregivers are employed was requested and granted before undertaking the research. The issue of keeping information from the interviews confidential was also clarified with management before the study was conducted.

3.6 LIMITATIONS OF THE STUDY

- The questionnaire and the scale were in English, which was none of the participants' first language. However, it was a requirement for the caregivers to have some level of education in order to complete the courses offered for caregivers at the hospice. Therefore the interviews were conducted in English. The pilot study was conducted on English second language speakers. The feedback from the pilot study assisted the researcher to simplify the questions and make sure that the participants were given the same explanations. However none of the items on the scale were edited or simplified as it did not seem to be a challenge for the participants.
- In addressing and answering the questions that required describing and exploring emotional perceptions, feelings and experiences, it appeared as though the participants did not totally open up during the interviews. This was attributed to the lack of trust despite the reassurances about keeping their responses confidential and their identity anonymous. The issue here might have been the relationship between management and the caregivers.
- Hudnall Stamm (2010) argues that when people feel that they are being observed or tested for 'bad' behaviour, they are unlikely to freely and truthfully participate in the study. It was therefore crucial for the researcher to explain what the test was all about before the interviews with each participant. The discussions regarding the scale might have influenced how the participants answered the questions on the scale.
- None of the participants consented to the use of a tape recorder during the interviews. As a result the researcher was not able to always record direct quotations from the participants. The researcher might have missed out on valuable information while focusing on writing out the responses to ensure that direct quotes were also captured. The issue of validity and reliability of the findings might also be questionable.
- The sample consisted of 15 caregivers which could be considered to be a small sample for a mixed method research. Therefore, the results of this study could not be generalised and also could not be transferable.

3.7 CONCLUSION

This chapter outlined the research methodology used in the study. The methods of data collection and analysis were also outlined. The instruments used to collect data were also discussed in this chapter. Reliability and validity on the ProQol scale was also discussed. The chapter also discussed ethical considerations as well as the limitations of the study. Chapter 4 presents the main findings, and Chapter 5 presents the conclusion and recommendations for future research and for the organisation where the participants are employed.

CHAPTER 4

INTRODUCTION

Chapter three provided details of the research methods to be applied in the data collection process. This chapter will focus upon the data analysis and the discussion of the research findin1gs. Data were analysed in order to ascertain, describe and explore the level of secondary traumatic stress, compassion satisfaction and burnout experienced by the caregivers at the hospice. Data were obtained from the ProQol scale (2009) and the semi-structured interview schedule to determine the participants' levels of burnout, compassion satisfaction and secondary traumatic stress.

4.1 DISCUSSION OF FINDINGS

As data was being processed and analysed, recurrent themes and sub-themes were identified from the semi-structured interviews.The caregivers' responses from the ProQol scale (2009) were used to analyse their level of secondary traumatic stress, compassion satisfaction and burnout.

4.1.1 *DEMOGRAPHIC PROFILE*

This set of data was intended to describe demographic variables of the sample and to assess if the data had any influence on the research findings. The demographic data consisted of age, gender, race, work experience and training received.

4.1.1.1 Gender of Participants

All the 15 caregivers that participated in the study were female. This does not necessarily mean there are no male caregivers; however, there are more female caregivers at an estimated 66% than male caregivers at 34% according to the National alliance of Care giving and AARP (2009).

4.1.1.2 *Age of Participants*

Participants were asked to state their age and none of the 15 participants were below the age of 30. This could be attributed to the fact that people below this age group were more likely still to be at school or furthering their studies, not forgetting the unemployment rate in this country especially amongst the youth. Three of the participants were between the ages of 31 and 35; five were between the ages of 36 and 40; while three were between the ages of 41 and 45 and two of the participants were between the ages of 46 and 50. There were no participants above the age of age of 61 and this is most likely because the retirement age in South Africa is above 65 years of age.

Care giving is an emotionally demanding work; therefore certain age groups might find it difficult to carry out the tasks expected from them (Wright, 2004). There is a strong correlation between age and the levels of compassion fatigue, secondary traumatic stress and burnout among caregivers. The younger caregivers might be at a higher risk of experiencing burnout, compassion fatigue and secondary traumatic stress, than older caregivers (Miller, 2000). However, Moodley (2001) argues that issues of personal characteristics of caregivers should also be considered as they might have an influence in how caregivers experience secondary traumatic stress and burnout.

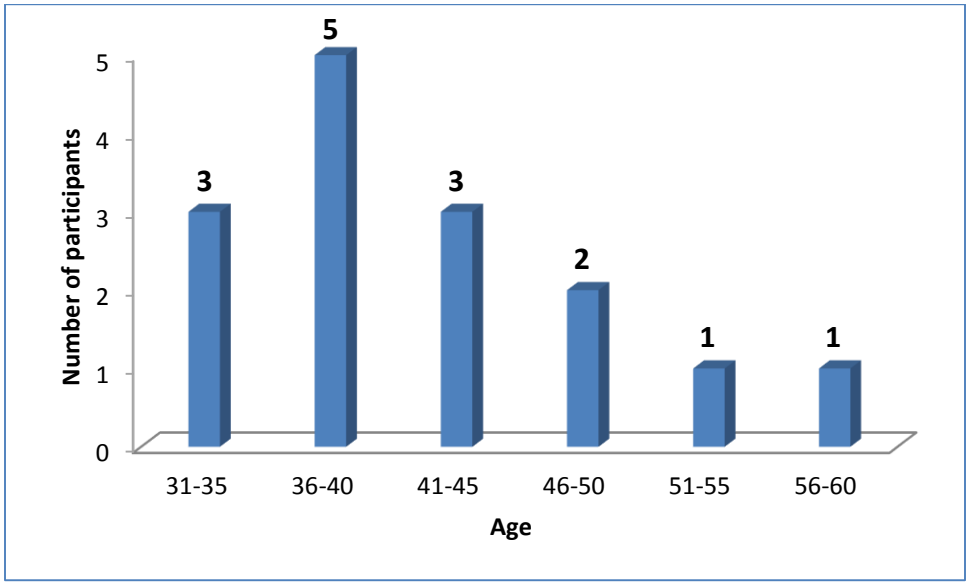


Figure 1: Age ranges of the participants (N=15)

4.1.1.3 Race of Participants

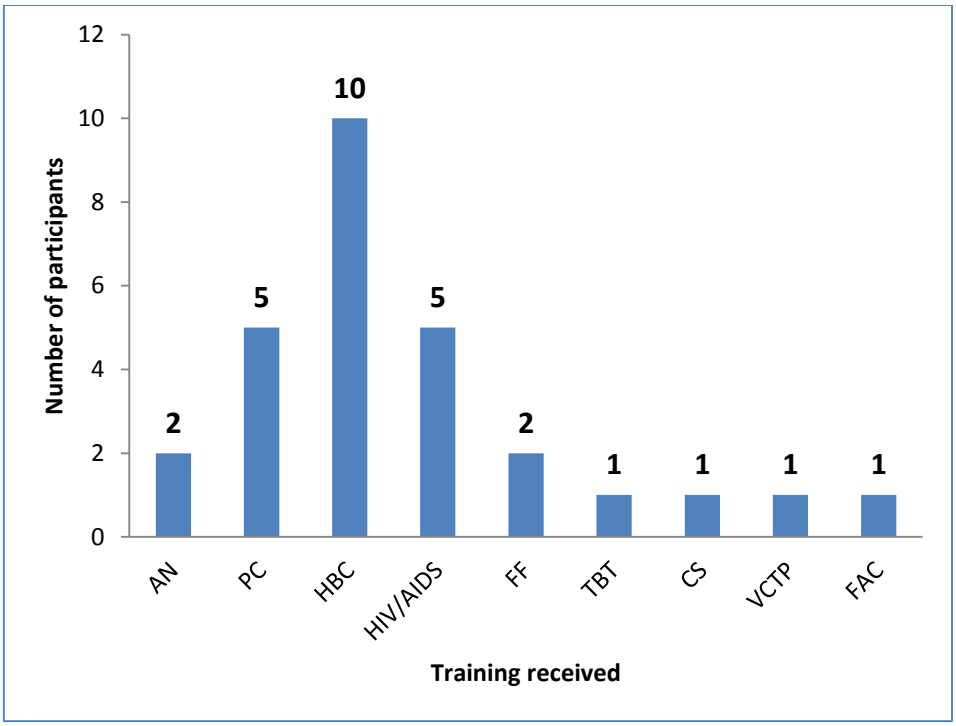
All the respondents who participated in the study were black. The fact that all caregivers in the employment of Sparrow Ministries Hospice were black is just a natural development in terms of the caregiver population and the service area of the organisation.

4.1.1.4 Marital status of participants

The 15 participants in the study were single; none of them had ever been married. This does not necessarily mean that they did not have children and families. For this study, however, caregivers were not asked about whether they had children or not. Single parenting in South Africa is not an unusual scenario; a lot of children are raised by single parents. However, being single and living alone might have a negative impact on the caregiver and how they cope with the aspects of their work. Living alone might result in the caregiver not having anyone to share their work experiences with when they get home.

4.1.1.5 Type of training received

All 15 participants had received various forms of training to equip them as caregivers. All 15 caregivers indicated that they had received more than one training course, namely Home Based Care, Palliative Care, HIV/AIDS, Tuberculosis Training and Auxiliary Nursing Diploma. The reason for inquiring about the training received was to find out if the respondents had the essential qualifications and requirements needed for a caregiver job. The organisational behaviour model argues that people tend to get stressed at work when the requirements of their job exceed their skills, knowledge and capabilities. For this particular study one can safely say the participants had received the necessary training to perform their jobs; however, it was not determined if the training had any effect on their compassion satisfaction, burnout or secondary traumatic stress levels (Staines, 2000).



Code

AN = Auxiliary Nursing Diploma

PC = Palliative care

HBC = Home Based Care

HIV/AIDS = A training in HIV/AIDS

FF = Fire Fighting course

TBT = A training in Tuberculosis

CST = Counselling Skills Training

VCT = Voluntary Counselling and Testing

FAC = First Aid Course

Figure 2: Training received by the participants (N=15)

Table 1 below displays the themes and sub-themes that emerged from the semi-structured interviews' data analysis. Six themes were identified and each theme had sub-themes.

Table 1: Emerging themes and sub-themes from semi-structured interview (N=15)

• Themes	Sub-themes
1. Compassion Satisfaction	1.1 Noticing an improvement in seriously ill patients 1.2 Seeing families of the patient happy and grateful 1.3 Working with children admitted at Hospice 1.4 Combating the effects of HIV/AIDS
2. The caregivers' understanding of the concept of burnout	2.1 Emotional exhaustion 2.2. Cynicism 2.3 Personal efficacy 2.4 Signs and symptoms of burnout
3. Compassion Fatigue	3.1 Challenging factors in caring for people living with HIV/AIDS 3.2 A significant shift in the level of compassion 3.3 Effects of a shift in the level of compassion 3.4 Work-life balance
4. Caregivers' personal coping mechanisms in dealing with burnout	4.1 Personal coping strategies 4.2 Support systems 4.3 Activities to relieve stress and burnout
5. Professional support services offered by the hospice to caregivers in dealing with burnout	5.1 Availability of services 5.2 Knowledge about the services offered 5.3 Accessibility of services
6. Addressing challenges faced by hospice caregivers	6.1 Working hours 6.2 Incentives and stipends

4.1.2 COMPASSION SATISFACTION

In the interviews 13 caregivers revealed that they experienced compassion satisfaction in the execution of their caregiving roles at the hospice. The caregivers are driven by their innate love for the health and wellbeing of every human being and by the spirit of ubuntu. Compassion satisfaction is defined by Stamm (2009), as the positivity involved in caring for another; this is a person's ability to derive gratification from caregiving. The various aspects of compassion satisfaction that were revealed by participants will be discussed in detail.

Table 2 below shows the participants' responses from the 2009 ProQol scale measurement of compassion satisfaction. From the responses it can be seen that ten of the 15 participants acknowledged that they like their work as a helper most of the times; only two participants rarely liked being a helper. Eight participants were very often happy that they had chosen their current work and ten of the 15 were proud of what they can do. These responses coupled with the responses from the interviews where the caregivers found satisfaction from the patients' health improvements and how they enjoyed seeing patients get better indicate that caregivers at the Sparrow Ministries Hospice did have a sense of compassion satisfaction in their work.

Table 2: Participants' responses on comparison satisfaction (N=15)

Statements	Very Often	Often	Sometimes	Rarely	Never	Total
I get satisfaction from being able to [help] people.	7	5	1	2	0	15
I feel invigorated after working with those I [help].	2	3	7	2	1	15
I like my work as a [helper].	10	2	2	1	0	15
I am pleased with how I am able to keep up with [helping] techniques and protocols.	9	3	2	1	0	15
My work makes me feel satisfied.	5	3	3	1	3	15
I have happy thoughts and feelings about those I [help] and how I could help them.	7	5	3	0	0	15
I believe I can make a difference through my work.	7	6	2	0	0	15
I am proud of what I can do to [help].	10	2	2	1	0	15
I have thoughts that I am a "success" as a [helper].	8	6	0	1	0	15
I am happy that I chose to do this work.	8	6	1	0	0	15

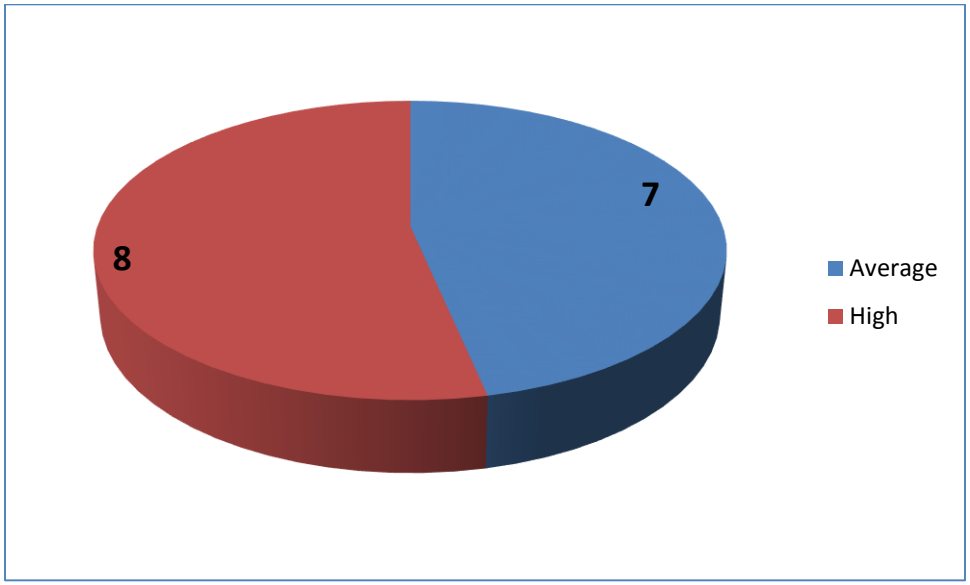


Figure 3: Number of caregivers and their level of compassion satisfaction (N=15)

Figure 3 above shows how much level of compassion satisfaction the participants at the hospice have. The caregivers at the hospice experience an average to high compassion satisfaction with eight out of the 15 participant caregivers having a high level of compassion satisfaction while seven have an average level compassion satisfaction. None of the participants in the study had a low level of compassion satisfaction. The caregivers attributed their level of satisfaction mainly to seeing improvements in their patients coupled with the good relationships and appreciation they get from the patients' families.

4.1.2.1 *Noticing Improvement In Seriously Ill Patients*

Most of the participants stated that what keeps them moving forward and going strong in their roles as caregivers at the hospice is noticing improvements in the health of the seriously ill patients. However, stating how many caregivers mentioned that was rather difficult as they used different phrases, but all referred to the same response. For example Participant 11 said:

"I feel good when a patient comes into the hospice in a bad state and they get better."

Participant 5 mentioned that:

"I feel satisfied when a life of a patient is restored due to my help."

Participant 2 said:

"I feel happy when I see a patient that was very sick, getting better and being discharged."

For some this is an enjoyable aspect of their job, while for others this is the greatest satisfying factor of their role as caregivers.

It is important for caregivers to have a sense of satisfaction with the work they do, according Mullins (2009). Healthcare workers and caregivers who work with people terminally ill with HIV/AIDS are more likely to provide better care services to patients when they are satisfied in their roles. Compassion satisfaction as discussed earlier in the paper, it derives from the good feeling of being able to do one's job properly.

4.1.2.2 Seeing Families Of The Patient Happy And Grateful

A study conducted by Nicholas, Christakisa and Theodore (2003) shows that there is a relationship between care given to patients and the effect it has on the families. A good and respectful relationship between caregivers and families gives job satisfaction to the caregivers. In the study six of the participants stated how they experience compassion satisfaction in the execution of their caregiving roles at the hospice when they see the families' happiness when a patient is experiencing health improvement; Participant 3 said:

"I feel blessed when l see their families happy."

Some families even go to the extent of showing the caregivers gratitude when they meet them in the community:

"When you meet them (families) later on in the community, they recognise and value you as a caregiver" (Participant 14).

The responses quoted above show that caregivers find satisfaction when they are recognised and appreciated for their good work by patients' families and the community.

The work environment such as hospice could pose many stressful challenges for caregivers which could lead to loss of interest in one's job. Working with people have experiences trauma in their lives may disrupts the social functioning of the caregiver (Stein, 2000). Human beings need to be recognised for the work they do, that is why some of the participants felt good when their work was recognised by family members of the patients.

4.1.2.3 Working With Children

All the 15 caregivers are of the view that working with children, although demanding, has high rewards. Five caregivers find satisfaction in working with children because they believe they can make a difference in the children's lives on a daily basis. These are the children who are admitted in the hospice with their parents or alone. Some of the children are terminally ill and some are affected by their parents' situation. Participant 6 said:

"l enjoy working with kids, l have a lot of passion and patience for kids and love to watch them grow appropriately."

The caregivers treasure and value healthy children admitted at the hospice as mentioned by Participant 15:

"What is satisfying for me is seeing a child that was once on an oxygen tank now breathing freely without an oxygen machine."

4.1.2.4 Combating the Effects Of HIV/AIDS

Twelve participants stated that they became hospice caregivers because they wanted to help to combat the effects of HIV/AIDS. For example Participant 10 said:

"I became a caregiver when an epidemic became a huge issue in my community and after watching my neighbour suffering because of HIV/AIDS."

These participants felt that this group of people was not being accorded the necessary care, protection and love that they deserved in the communities and hospitals. Participant 9 said:

"I have been watching poor treatment of people living with HIV/ AIDS both in the hospitals and communities; as such, I wanted to help them."

The caregivers feel there is still stigmatisation against people living with HIV/AIDS both in hospitals and the communities as mentioned by Participant 2:

"I have a family member that has died of HIV/AIDS, so I became a caregiver in order to help families to deal with denial and stigma associated with the disease."

Five caregivers had wanted to be in the medical field. A failure to qualify for a nursing diploma made them choose to be hospice caregivers, since they would still be in the medical field

"I wanted to become a nurse but did not qualify due to low marks. I decided to become a caregiver in order to get the expertise and experience of helping a family member that has been diagnosed with HIV."

"I have always wanted to help people who are sick and I hope that one day I will become a nurse," said Participant 7.

In 2011 President Jacob Zuma announced a strategy to improve South Africa's fight against HIV/AIDS. Some of the South African National Strategic Plan's objectives are to sustain health and wellness, primarily by access to quality treatment, care and support services, and to develop programmes that focus on wellness; to reduce the self-reported stigma related to HIV and TB by at least 50% of sufferers. It is not surprising that participants find satisfaction with their work because they have a purpose and a cause that they are fighting for which is also part of the nation's goals. This implies that the fight against HIV is universal and supported in South Africa, but there is still so much to be done about the stigma attached to the illness.

Experiencing high compassion satisfaction with moderate to low burnout and STS is considered a very positive result in the workplace. Individuals who receive positive support are said to experience these scores. At the hospice about eight of the respondents experienced high CS and also experienced average to low burnout and STS. The remaining seven caregivers experienced average CS coupled with average to low burnout and STS. This experience, however, cannot be linked to the caregivers receiving reinforcement and support in the workplace as many of them complained in the interviews that they did not have good relations with the management

4.1.3 BURNOUT

4.1.3.1 The Caregivers' Understanding Of The Concept Of Burnout

Burnout is associated with the feeling of helplessness and an individual having difficulties in dealing with their work. Nine participants indicated that they are fully aware and understand the concept of burnout.

Table 3 below shows the levels of burnout experienced by the respondents as measured using the ProQol scale. The caregivers in this study did experience burnout in their work with nine participants stating that they felt like they were not the person they always wanted to be, while eight participants stated that they were never a very caring person and eight participants never really felt connected to others. Burnout does not only affect the caregivers but anyone who is in contact with them, including patients, with some patients reporting low satisfaction with the services provided (Austin,Globe,Leier & Bryne, 2009; White, 2006). This could possibly be why some of the caregivers at the hospice felt they were not caring people, and did not feel connected to the patients.

Table 3 Levels of burnout experienced by the respondents as measured using the ProQol scale

Questions	Very Often	Often	Sometimes	Rarely	Never	Total
I am happy	2	1	5	4	3	15
I feel connected to others.	0	2	0	5	8	15
I am not as productive at work because I am losing sleep over traumatic experiences of a person I (help).	5	0	6	4	0	15
I feel trapped by my job as a [helper].	5	0	5	2	3	15
I have beliefs that sustain me.	2	1	4	2	6	15

I am the person I always wanted to be.	0	0	1	5	9	15
I feel worn out because of my work as a [helper].	2	0	6	2	5	15
I feel overwhelmed because my case [work] load seems endless.	1	1	10	1	2	15
I feel "bogged down" by the system.	5	3	3	2	2	15
I am a very caring person.	0	1	2	4	8	15

Table 3: Participants' responses on burnout (N=15)

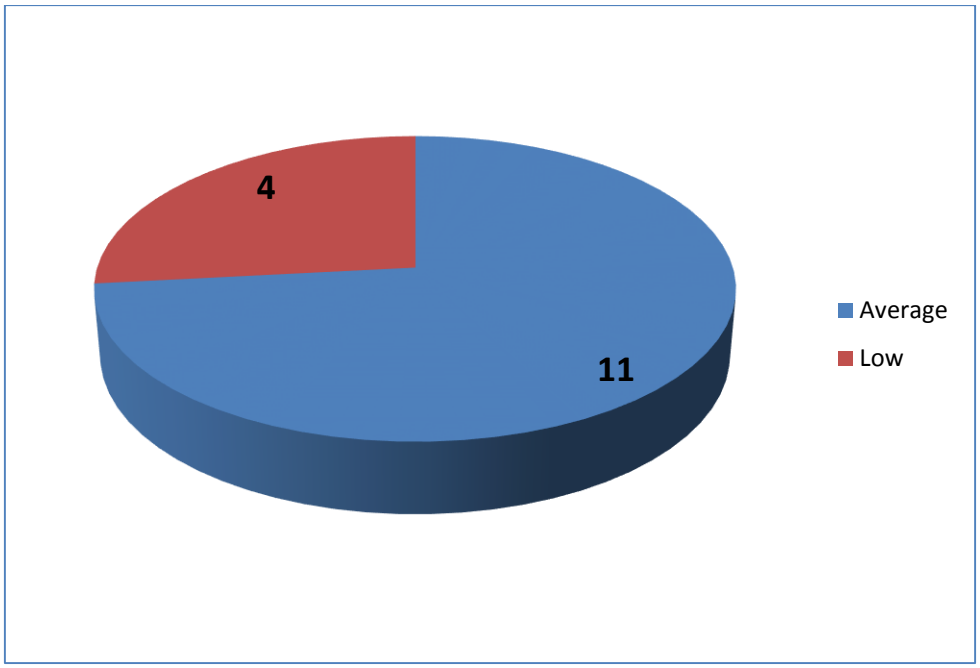


Figure 4: Number of participants and their level of burnout (N=15)

Figure 4 above shows the caregivers' level of burnout. The caregivers experience average to low burnout with 11 caregivers having average burnout level while the remaining four caregivers

have a low burnout level. None of the respondents scored high burnout levels, which is a good indication of the caregivers not being highly stressed by their work; high levels of burnout have often been linked to many professionals quitting their work, which would put a strain on the already challenging and struggling caregiving profession. According Bruce & Sangweni (2012) there is an undesirable association between levels of burnout and job satisfaction. This means that people with high burnout levels are not satisfied with their jobs; on the other hand looking at the level of burnout of caregivers who participated in the study one can safely say the caregivers do experience some form of satisfaction in their work and this is attributed to the average to low burnout levels. During the interviews the burnout issues that emerged had to do with emotional exhaustion; cynicism; personal efficacy; signs and symptoms of burnout.

4.1.3.2 Emotional Exhaustion

The responses of the 15 participants varied regarding the issue of emotional exhaustion. Participant 8 said:

"I feel exhausted emotionally due to the fact that l try to be perfect in my job but l do not receive any recognition or appreciation from the management, all I get are complaints."

According to Boyle (2011, p. 12) caregivers need to be alert for compassion fatigue and burnout danger signals such as always blaming others, complaining and self-medication.

Two caregivers felt that although emotional exhaustion comes from the demands of the caregiving job, they often get frustrated emotionally when patients are not getting better. "It is emotionally exhausting to care for one patient for a long time but no seeing any improvements on their medical condition" (Participant 8).

Emotional exhaustion refers to not having the capacity to offer psychological support to people who have experienced trauma. This could be a challenge for caregivers caring for terminally ill patients as they might not be able to offer support to their patients (Mcmann & Pearlmann, 2002).

At times the loss of patients causes emotional exhaustion. Participant 2 said*:*

"Sometimes you get too attached to the patient and when you come for duty the following morning you find that the patient had died, that is so dissatisfying and traumatising."

According to Miller (2000) emotional exhaustion and burnout occur when one feels overwhelmed and unable to meet constant demands. As the stress escalates one tends to lose motivation that led them to take on the job. Participant 5 said:

"I nearly left this job due to the way l was treated in front of patients and colleagues."

Lack of appreciation was identified by respondents as causing exhaustion; caregivers feel they work hard to care for their patients and are not appreciated, as mentioned by Participant 3:

"Treatment from management causes such feelings and I end up not caring well for patients."

Unfortunately data was not collected from the management to get a better understanding of the challenges at the hospice.

On the other hand five participants stated that they did not feel emotionally exhausted mostly because their job does not allow them to be emotionally exhausted; all they want to do is to help the patients, as said by Participant 13:

"I never get emotionally exhausted because l always tell myself that l am here to work ... The fact that I am at work I have to focus on my work, my patients need me."

This could be that these caregivers might not fully comprehend the meaning of emotional exhaustion or it could be a coping mechanism strategy to deal with the work challenges (Wright, 2004). The organisational behaviour model terms this coping mechanism a cognitive method of dealing with stress at work whereby an individual develops resilience and accepts the work demands.

4.1.3.3 Cynicism

Eight respondents stated that at times they feel like avoiding and not helping the patients, Participant 2 said:

"Some patients have serious and highly infectious conditions and diseases. They have dangerous diseases, so l try avoiding them so as not to get infected."

The participants stated that at times they avoid patients because they mistreat them and because some patients are in denial of their HIV status.

"I avoid and feel like not helping some patients because some of them are very difficult to handle and accuse us as caregivers of stealing things from their rooms" (Participant 15).

"I avoid patients who are on denial for example, who do not want to accept that they are HIV positive, making it difficult for caregivers to assist them" (Participant 3).

Two participants, however, attributed cynicism to their own personal issues which they then take out on patients. Participant 11 said:

"Sometimes l avoid helping patients, but it would not be because of their situation but because of my own issues."

Three participants attributed cynicism to the desire to avoid being attached to patients who are too sick and could possibly die. Participant 6 said:

"I do feel like avoiding the patient if there are no changes on the patient's condition."

According to Figley (1995), burnout is characterised by cynicism, also known as depersonalisation. An alienated and impersonal, cynical, uncaring attitude towards clients is what characterises burnout. It also occurs when one does not feel good about what they do and always have hard time seeing the good in others (Pross, 2006).

For six participants however, even when patients ill treat them and even when the environment is not conducive to empathy, they always try to be empathetic to the patients and their situation. Participant 13 said:

"I try and have empathy for them even when they mistreat me."

This could be attributed to the fact that the six participants have experienced high compassion satisfaction or they might also using this strategy as a coping mechanism. The other factor might

be that the participants are too cynical about their work, but rather avoid certain parts of their work that might be difficult to cope with.

4.1.3.4 Personal Efficacy

Miller (2000) defines self-efficacy as the strength of one's belief in one's own abilities to complete tasks and reach goals. Thirteen participants had challenges in believing in their own abilities and own potential because they felt unhappy in their work as caregivers and it was attributed to their unhappiness with the working conditions at the hospice. Their responses below shows their dissatisfaction with the conditions at work and also with the management of the hospice.

"The management has a bad style; they do not want us to take a break or leave."

And Participant 10 said:

"The shifts just get changed abruptly, at times when you report for duty; you find that a shift for the following day has been changed. This does not give you enough time to mentally prepare for work."

Lack of appreciation and constant criticism by staff tend to lead to low self- esteem. For example Participant 8 said:

"I feel unhappy when colleagues do not speak properly to me and at times when they gossip and say bad things about me."

Participant 13 said:

"Being undermined by management and nurses at the hospitals."

Two of the participants attributed their unhappiness to the difficult clients that they handle.

"I feel unhappy when handling a difficult patient." However this could also relate to the lack of appreciation of caregivers when they have done a good job.

On the other hand two caregivers are demotivated due to the differences and disparities that exist in the remuneration structure:

"It is so demotivating that we work together, do the same job and work the same shifts but do not get the same amount of salaries, some get more, some get double than what others are getting."

However, the differences in salaries could be due to years of experience.

The organisational behaviour model focuses on understanding the behaviours and attitudes of individuals and groups in the workplace (Colquitt, Lepine & Wesson, 2009). The model recognises that there have to be good management structures in place in order to achieve organisational goals. Employees at times do not recognise systems that work; such attributions create a negative working environment and the focus shifts from what the job is about to systems that do not work. Sparrow Ministries Hospice is an NPO relying on donations and minimal state funding. The reality is that as much as caregivers might not be happy with the different salaries they receive from Sparrow; at least they are getting one. South Africa has a high rate of unemployment especially for the youth. It is therefore not fair to only focus on one side of the employees and ignore the kind of setting the hospice is.

4.1.3.5 Signs And Symptoms Of Burnout

The participants shared their personal signs and symptoms of what they deem to be burnout and they all had almost similar signs and symptoms. The reported symptoms were grouped into physical, emotional and behavioural symptoms. The symptoms identified by the participants have been identified by a lot of scholars as causing burnout. Figley (1995) identifies clinical indications of burnout as including, but not limited to, fatigue, headaches, eating problems, sleeplessness, irritability, emotional flux, and strain in relationships with other people. The identified clinical symptoms are not any different to the symptoms experienced by the participants in the research.

All the participants in the study experienced physical symptoms of burnout and identified symptoms such as sore feet, sweating a lot, high blood pressure, backaches, headaches and dizziness. Thirteen of the participants experienced emotional symptoms which include tiredness,

mood swings mostly towards their families, short temperedness, and lack of energy and loss of compassion. Nine participants experienced behavioural symptoms from being irritable to having difficulty waking up. Carter (2002), states that caregivers may have problems with their sleep patterns which can cause depression and even chronic illnesses. The hospice setting places caregivers in a vulnerable position to experience burnout. The fact is, the kind of work the caregivers do requires a lot of emotional involvement based on the kinds of patients they caring for. Strategies to help caregivers deal with these symptoms become very crucial and necessary.

Burnout in the workplace is usually associated with psychological patterns which come to be as a result of relational stressing issues on the job. Caregivers who experience high levels of burnout not only put themselves at risk but they also put the lives of their families and patients at risk. For this particular study, none of the participants experienced high burnout while experiencing average to low CS and STS. However, seven of the participants did score average burnout coupled with average CS and low STS. This is positive for the hospice and of great health benefit for the caregivers as they do not have high burnout levels and had low STS levels.

A study carried out by Meldrum, King and Spooner (2002) shows that about 27% of the professionals who work with people in trauma experienced extreme distress as a result of their work. They also found out that 54.8 % were distressed at the time of the study and 35.1% were extremely drained emotionally

4.1.4 *CAREGIVERS' PERSONAL COPING STRATEGIES IN DEALING WITH COMPASSION FATIGUE, SECONDARY TRAUMATIC STRESS AND BURNOUT*

The participants were very elaborate in their responses on how they cope and deal with compassion fatigue, secondary traumatic stress and burnout. In their responses, they elaborated on their personal coping strategies, their support systems and on the activities that they do to relieve stress. However it should be noted that none of the caregivers mentioned any clinical strategies such as counselling in order to cope with the impact of caring for terminally ill patients. These issues will be discussed next as sub-themes.

4.1.4 Personal Coping Strategies

The participants stated that they implement several strategies in looking after themselves when they are not at work. They mentioned similar coping mechanisms which include relaxing activities like reading, physical activities such as exercising, religious activities such as praying and social activities like chatting with friends.

Self-care planning is a smart choice and of great benefit to the challenges faced in hospice. According to Jones (2005) by mapping a plan that addresses individual physical, emotional, cognitive, relational, and spiritual strengths and challenges, individuals can help themselves monitor the difficulties of a hospice career in order to avoid burnout, keep motivation, and address hindrances. A study conducted by Amir (2013) shows that burnout and compassion fatigue may be alleviated using, among other strategies, engaging in social activities, exercising, spending time with family, developing a spiritual life.

4.1.5 Support Systems

The literature shows that caregivers are in need of protection from physical and emotional harm. They need to have some form of support in order to help them get through the challenges and stresses they experience at work. Responses from the interviews indicate that the caregivers draw a lot of support from various sources in order to deal with the challenges they experience at the hospice. The most common sources of support were families, friends, colleagues and partners.

4.1.6 Activities to relieve stress and burnout

Caregiving demands can be overwhelming for an individual, especially if they feel they have no control over the situation at hand. If left unattended to, the stress can have an adverse effect on the caregiver's health, relationships, and state of mind, which would eventually lead to burnout. The participants stated that they do engage in a lot of personal activities to relieve stress and burnout. Participant 2 said:

"I sleep a lot, play games and puzzles with my kids, plus reading comic magazines."

Cooking, going to church, socialising and cleaning help take the caregivers' minds off the realities of their work environment.

4.1.5 COMPASSION FATIGUE

Boyle (2011) postulates that compassion fatigue develops when caretaking plans are ineffective; this leads to the caregiver feeling misery and having a sense of guilt. Some authors use the compassion fatigue interchangeably with the concept of secondary traumatic stress. The majority of the participants stated how they face challenges when caring for HIV/AIDS patients and as a result their attitudes towards hospice patients have significantly changed from the time they started working at the hospice. This is greatly affecting their work, as others claim that they find it difficult to draw the line between their personal life and work life. Below is a further discussion of the issues related to compassion fatigue and secondary traumatic stress as viewed by the participants.

4.1.5.1 Challenging Factors In Caring For People Living With HIV/AIDS

In the study all the participants were of the view that the most challenging factor about being a caregiver is caring for people living with HIV/AIDS. Although the participant did not acknowledge being traumatised by the situations experienced by their patients, it was clear in some of their responses that there were certain experiences of secondary trauma.

Participant 1 said some of the challenges included:

"Immobile patients, stroke patients, helpless patients who cannot walk, changing nappies for adults, lack of medication, administering medication, patients admitted for long at hospice."

Participant 4 said:

"Denial from patients, refusal to take medicines/treatments and patients abandoned by family."

Seven caregivers felt that as much as they love their work and do it for the spirit of ubuntu, there are no pre-exposure prophylaxis medicines to ensure their safety, so they can be at risk of infection or worse. These experiences could be traumatising to the caregivers and would have an

impact in how they treat the patients which could be attributed by fear of being infected themselves.

Participant 10 said:

"There is lack of resources and professional medical staff to attend to very sick patients."

And Participant 1 said:

"I fear getting infected by TB from some of the patients."

Some of the patients' health conditions do not improve and this leaves a sense of helplessness for the caregivers and thus burnout levels can increase, as said by Participant 9:

"Sometimes there is no progress on the condition of patients."

The fact that HIV has no cure was stated by the caregivers as one of the challenges:

"The reality that there is no permanent cure for HIV."

"My fear is losing a patient to death due to illness."

All these factors can only leave one exhausted from the work of trying to deal with the challenges and thus indicating that caregivers do experience compassion fatigue.

In 1998 Wilson carried out a study on trauma counsellors in South Africa. The counsellors experienced feelings of powerlessness, hopelessness, and a sense of detachment from others. Compassion and empathy to the terminally ill therefore tends to have a negative effect on the caregivers.

4.1.5.2 A Significant Shift In The Level Of Compassion

Boyle (2011) is of the view that compassion fatigue is related to personal connections that a nurse/caregiver has with their patients or their family. As the caregivers intensely witness the tragedy of losing patients in the workplace, they tend to disassociate themselves from their work and the people they work with.

On that note, 10 participants stated that they have realised a significant shift in the level of compassion that they have towards patients, compared to when they first started working as caregivers in the hospice.

Participant 3 said:

"I was motivated and eager to implement what l learnt during my training days ... but l am no longer motivated."

Some attributed this loss of compassion to the structural and infrastructural changes that have been happening at the hospice:

"I have lost compassion due to the changes in the structure of the hospice" (Participant 13).

Six participants felt the management style, low salaries and discrimination caused their loss of compassion. Participant 11 said:

"My compassion has declined due to … unfair treatment by the management, discrimination and long admitted patients."

They felt that the management does not recognise their good work; the organisational behavioural model stresses how conflicting expectations of employers and those of employees can cause work hindrances. Because the Department of Health is not providing training and lack of in-service training one caregiver felt this has caused them to lose their compassion. However none of the participants indicated how they have tried to get further training for themselves. This shows a lack of initiative by the caregivers.

"The compassion is long gone due to lack of in-service training and lack of skills development opportunities from the Department of Health" (Participant 7).

Stress and lack of compassion in the workplace is not always caused by work related issues; sometimes some stress from home can spill over into the workplace and vice versa (Colquitt, Lepine & Wesson, 2009). The shift in the level of compassion might not only be caused by the caregivers' experiences at work or their relationships with the management; it could possibly be due personal factors that spill over into their work life.

4.1.5.3 Effects Of A Shift In The Level Of Compassion

Eight caregivers noted a number of negative effects associated with the loss of compassion. These caregivers have experienced compassion fatigue, and what emerged is how interest towards work and towards patients has deteriorated, Participant 8 said:

"I try to avoid some of my duties."

Participant 5 said:

"You won't care for patients with love and compassion."

These were noted as effects of low compassion. As a result of the negative shift in compassion some of the participants no longer go an extra mile in the execution of their duties

"I now treat it as a job and do not make any extra effort. I just do it so as to get paid."

Ebright (2010) argues that caregivers deal with urgent and life-threatening issues on a daily basis but rarely receive formal support to counter negative emotional effects of their work. This causes a negative shift on the levels of compassion, which tends to have negative connotations on both the caregivers and the patients. Figley (1995) is of the view that caregivers tend to experience compassion fatigue because they tend to be engrossed with their patients and as a result they re-live their trauma. As a result they tend to avoid situations that remind them of their work, and they suffer anxiety attacks. Secondary traumatic stress and compassion fatigue have severe effects on the levels of empathy caregivers have, which leads to distressing suppositions of self, their core beliefs and their world view (Howell, 2012). As a result the effectiveness of caregivers is impacted, which can result in increased risks, errors, ineffective treatment plans, and most probably mistreatment of patients (Bride & Figley, 2007).

4.1.5.4 Work-Life Balance

The participants' responses on work-life balance varied. Eleven caregivers stated that they are in a position to strike a balance between personal life and work issues and they attributed this skill to the fact that they receive adequate coaching and mentoring. Participant 10 said:

"When I am at work, l leave my family issues at home and vice versa. It's not easy but l received good mentoring."

Four caregivers stated that the lines between the two spectrums of life have become blurred because what happens in their personal lives influences what happens on their professional life and vice versa. As a result they fail to distinguish between their personal and professional lives. The participants also elaborated on their ability and failure to distinguish between personal and professional issues. Participant 15 said:

"It is not easy, sometimes the stress from work can spill over to the home environment and I find myself shouting at my children."

And Participant 7 said:

"I started working with kids here; l found myself shouting at my own kid which was not fair. My sister had to remind me to stop."

Participant 2 said:

"I can no longer separate what is personal from what is work related."

According to Jones (2008) hospice professionals need to have the ability to fully enter into relationships with patients while maintaining their own personal lives and wellbeing. Striking a balance between work, rest and their personal lives can help the caregivers reduce compassion fatigue, the organisational behaviour model states that stress spills over from work to home or vice versa and tends to cause challenges when it comes to managing behaviour in the workplace. This is because negative life events tend to impact in the employee's life and in turn cause a significant change in that employee's life. Lengthy empathic engagement with patients interferes with the caregivers' awareness of their own life experiences; causing detachment from self and others (Tyson, 2007).

4.1.6 SECONDARY TRAUMATIC STRESS

In response to the ProQol statements the caregivers did experience secondary traumatic stress. Table 4 below shows the caregivers' responses and 10 participants stated that they are at times

startled by unexpected sounds. Seven participants stated that they avoid certain activities or situations because they remind them of frightening experiences of the people they help. According to Cromer (2012), caregivers are at risk of developing secondary traumatic stress which highly affects their senses and emotions. Some of the caregivers find it difficult to separate their personal lives from those of their patients and Cromer (2012) says this is because the caregiver feels responsible for lessening the patients' suffering.

Table 4 Caregivers' responses regarding secondary traumatic stress

Questions	Very Often	Often	Sometimes	Rarely	Never	Total
I am preoccupied with more than one person I [help].	6	2	7	0	0	15
I jump or am startled by unexpected sounds.	3	0	10	0	2	15
I find it difficult to separate my personal life from my life as a [helper].	2	4	3	1	5	15
I think that I might have been affected by the traumatic stress of those I [help].	2	3	4	1	5	15
Because of my [helping], I have felt "on edge" about various things.	0	3	4	2	6	15
I feel depressed because of the traumatic experiences of the people I [help].	3	3	2	3	4	15
I feel as though I am experiencing the trauma of someone I have	4	3	4	1	3	15

[helped].						
I avoid certain activities or situations because they remind me of frightening experiences of the people I (help).	2	3	2	1	7	15
As a result of my [helping], I have intrusive, frightening thoughts.	1	2	6	0	6	15
I can't recall important parts of my work with trauma victims.	2	3	6	0	3	15

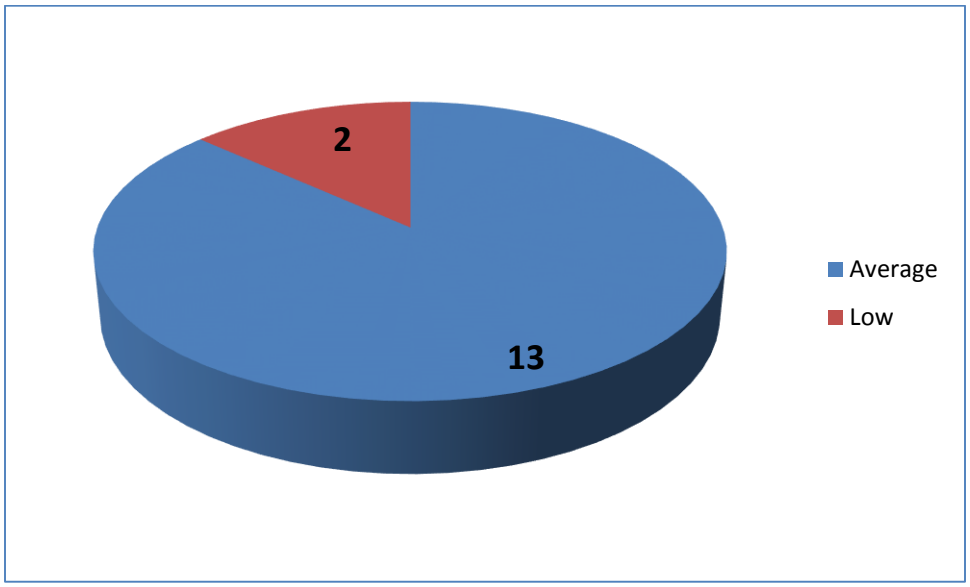


Figure 5: Number of caregivers and their level of STS (N=15)

Figure 5 above shows the level of secondary traumatic stress the respondents experience in their work. The caregivers have an average to low secondary traumatic stress level. Thirteen of the respondents experienced average levels of secondary traumatic stress, while only two experienced low secondary traumatic levels. The fact that more participants experienced average secondary traumatic stress levels as compared to the low secondary traumatic stress levels

indicates that a high number of the participants do experience secondary traumatic stress. During the interviews one participant stated that at times she carries the stress from work home, and even gets to shouting at her children. This particular example shows how STS can have effects on the caregiver and their family. According to Bloom (2003) people working in hospitals, hospices or dealing with sick people are prone to secondary traumatic stress. STS is an expected outcome of working with traumatised and sick people; thus caregivers at the hospice need all the emotional support they can get.

Those who usually experience negativity at work associated with fear are said to experience these kinds of scores. In this study none of the participants experienced high STS coupled with low burnout and low compassion satisfaction. Of the 15 participants none had experienced low compassion satisfaction and only average and high CS. However, in the interviews some participants did express a sense of fear in their line of work. Because the caregivers deal with people living with HIV/AIDS they expressed fear of being infected: "No precaution medicines for our safety." In spite of this none of the caregivers were at a high risk of secondary traumatic stress. Self-care is also necessary as it will ensure that the caregivers are also taking responsibility for their own coping and performance at work.

4.1.7 PROFESSIONAL SUPPORT SERVICES OFFERED BY THE HOSPICE TO CAREGIVERS IN DEALING WITH BURNOUT.

Caregivers need short-term stress-management and coping support systems to assist them become highly effective in the execution of their work, as they get a safe emotional space to identify feelings and thoughts related to their work. Ten caregivers said they did not have knowledge of professional support services and it hindered the execution of their work

4.1.7.1 Availability Of Support Services

According to ten of the participants, they were not aware if the hospice offered any professional support services in helping them deal with the impact of caring for terminally ill patients. This could lack of awareness with regards to the services or caregivers might not understand the need of having such services.

"There are no support services offered, we are left to deal with challenges in our own way" (Participant 1).

One caregiver confirmed that no debriefing or counselling services are offered after the death of any of their patients

4.1.7.2 Knowledge About The Services Rendered

It was evident that some of the caregivers did not understand the kind of services that they should be provided with in order to deal with secondary traumatic stress, compassion satisfaction and burnout. However some were aware and even mentioned some of the services such as counselling and debriefing.

"There is no counselling or debriefing offered to us, especially when a patient dies" (Participant 3).

4.1.7.3 Accessibility Of Services

The caregivers at this hospice have a daunting task of caring for patients who are terminally ill. It is therefore crucial to have access to professional support services in dealing with the impact of the caring job. Based on the responses with regards to the services offered to caregivers by the hospice, one could mention that it seemed as there is lack of awareness on the issues of self-care. That was attributed by the fact that ten participants were not aware of any support services offered by the hospice. It would be necessary for such services to be made accessible to all caregivers caring for terminally ill patients at the hospice. Such services could be made free of charge and easily accessible. This would be mentioned in the recommendations chapter.

It has been discussed in the literature review that lack of professional support services could lead to compassion fatigue and burnout on the caregivers.

Because caregivers are relied upon to help others, they need proper support systems to be able to do their jobs properly, but they often do not get the help they need the most. The greater challenge is that the most accessible support services are costly: i.e. the hospice has to pay for

private consultants or the caregivers have to pay for themselves to have access to these services. A need for free counselling services becomes crucial in a hospice setting where funding is minimal.

4.1.7.4 Addressing Challenges Faced By Hospice Caregivers

The participants proposed numerous solutions to addressing the challenges they face in the execution of their duties as caregivers. Basically, the recommendations have to do with infrastructural, institutional, structural, policy and procedural changes and reforms.

4.1.7.5 Remunerations Policies And Procedures

The caregivers felt there needed to be a fair and transparent remuneration structure from the hospice management.

"Salaries need to be increased and the remuneration structure needs to be fair, all the caregivers should get the same salary" (Participant 3).

Sparrow Ministries Hospice is an NPO relying mainly on donors and minimal state funding. The reality is that the stipends being paid to the caregivers are what they could afford. The issue of equal stipends might be a challenge as in the interviews it was proven that the participants did not have the same years of experience. Therefore the salary scales might differ due to the number of years as a caregiver at the hospice.

4.1.7.6 Incentives And Recognition Of Good Work

They requested better relations with management which involved respect, transparency, accountability and recognition for their efforts. They also requested training and skills development courses, counselling and debriefing sessions.

However, looking at the solutions suggested by caregivers, none focuses on emotional challenges rather structural issues with management. Since the management of the hospice was not part of the interviews for this study, it is therefore difficult to only focus on the side of the caregivers

and their demands. For future research it would be beneficial to look at both sides of the story to make good conclusions and recommendations.

The researcher's motivation for this study came out of an observation through rendering social work services to caregivers, patients, patients' families in 2004 at FWC Hospice. The researcher had to offer counselling and debriefing sessions to caregivers. However, in the sessions, caregivers mentioned that most of their challenges had to do with the treatment they receive from management. It appeared as if caregivers did not want to focus on the emotional and psychological impact the work has on their personal and professional lives.

This could be understandable as according to Crandal & Perrewe (1995), an imbalance between the job demands, working conditions and lack of resources could lead to dissatisfaction and loss of interest in work by employees. Based on these findings from caregivers at Sparrow Ministries Hospice, caregivers might be using this as a coping mechanism which prevents them from introspecting and dealing with their emotions. Therefore a need for a review of the environmental structures of the hospice is necessary. It seemed as if the caregivers would begin to focus on their wellbeing if the issues such as : work schedules, working hours, incentives and stipends were to be improved.

"The more you work here, the more you become de-motivated due to the bad treatment that you get from the management" (Participant 7).

Those who experience the average CS, burnout and STS could be because they are no longer interested in their work as they used to, Participant 7 said

"I am losing passion and compassion regarding my work."

On average, despite all the one-sided challenges with management, a majority of the caregivers did like their work and the positive impact they brought into the lives of their patients made this possible (Hudnall Stamm, 2009).

4.2 CONCLUSION

The purpose of this chapter was to get a better understanding and knowledge of the extent to which the caregivers at Sparrow Ministries Hospice experienced compassion satisfaction, burnout and secondary traumatic stress as a result of their work. Both qualitative and quantitative methods were used to get a better view into the caregivers' lives at work. The challenges they faced and all that gave them satisfaction in the work they do. Thus pragmatic evidence was gathered and analysed for this purpose.

The results of the study, both qualitative and quantitative, indicate that more than half of the participants experienced high compassion satisfaction with average to low burnout and secondary traumatic stress. This could possibly be attributed to the ages of the participants and the reasons why they decided to become caregivers etc.; however, these assumptions are made solely based on literature as none of the questions in the study were for the purpose of determining the causal link between age and compassion satisfaction, or burnout or secondary traumatic stress.

The findings also show that neither the burnout levels of the caregivers nor their secondary traumatic stress were high. Those who had experienced some form of burnout attributed it to the bad relationships they had with the management, the frustrations that came from the patients not getting better and the constant thought that there was no cure for HIV/AIDS. The caregivers also mentioned that there were no professional support structures where they could have platforms for de-stressing. They either solely or mostly relied on family and friends for support, which is challenging because at times family may not understand what the individual is going through. These factors then might lead to burnout, as very few people are likely to access counselling services at a cost.

In conclusion, an environment such as hospice places caregivers at risk of experiencing burnout and secondary traumatic stress due to the nature of services offered to terminally ill patients. On the other hand caregivers could still enjoy and experience compassion satisfaction resulting from being able to perform one's tasks and duties. Caring for terminal ill patients brings about positive and negative aspects in the caregiver's life. Therefore, awareness on secondary traumatic stress, compassion fatigue and burnout in caregivers might help the management develop strategies that

may prevent the development of negative aspects of work. Caregivers might also become aware of the impact the work they do caring for terminally ill HIV/AIDS has on both their professional and their personal lives. The realisation by caregivers might assist them in not only focusing on structural challenges, but on better caring for their emotional wellbeing which in return could ensure professional quality of life

CHAPTER 5

INTRODUCTION

Chapter 4 dealt with the analysis and interpretation of data collected using semi-structured interviews and the ProQol scale. This chapter will present a summary of the research findings from the empirical investigation on caregivers caring for terminally ill HIV/AIDS patients at Sparrow Ministries Hospice on the levels of compassion satisfaction, secondary traumatic stress and burnout. The main findings of the study are presented in this chapter through integrating the main aim and the objectives of the study. The recommendations will serve as guiding principles to assist hospice management and other organisations employing caregivers providing palliative care services to terminally ill HIV/AIDS patients to ensure that caregivers are better looked after.

5.1 MAIN FINDINGS

The overall aim of the study was to measure compassion satisfaction, secondary traumatic stress and burnout on caregivers caring for terminally ill HIV/AIDS patients at Sparrow Ministries Hospice. The empirical investigation was initiated by the researcher's observations of the adverse psycho-emotional effect of care giving on caregivers, while she was providing social work services to the terminally ill patients and their families at FWC Hospice in 2004.

The research also sought to share findings with the management of Sparrow Ministries Hospice and other organisations which provide palliative care services to the terminally ill to assist them in offering better care service to their patients and caregivers. A detailed discussion of the objectives of the research with reference to the main findings is presented.

Objective 1: To explore how caregivers working at Sparrow Ministries Hospice understand the concept of compassion satisfaction, secondary traumatic stress and burnout.

Findings in the study indicate that nine of the 15 caregivers understood what burnout means and they even gave burnout symptoms they experience from physical to emotional symptoms. According to the caregivers the demands of the job leave them emotionally exhausted, with one caregiver mentioning how she gets so exhausted at times that she feels she cannot care for her

patients. Seven caregivers felt like avoiding patients sometimes due to the emotional stress they experienced.

The research findings according to the caregivers' responses indicate the hospice does not have enough resources; which partly has created caregiver cynicism towards patients. Resources included gloves, medication to prevent TB infections and painkillers. As a result caregivers tend to avoid patients in fear of infection because at times they do not have necessary protective clothing, e.g. gloves, when attending to patients.

Findings also show that some caregivers felt that the relationship between the caregivers and management has challenges and they regarded it as not a good relationship and some caregivers attribute their burnout to the relationship. Thirteen of the 15 caregivers felt unhappy in their work as caregivers and they attributed this mostly to their relationship with the management and difficult patients. Unfortunately for the purpose of this research data was not collected from the management to have a better understanding of the activities at the hospice and to get their views. Therefore future studies on this field could benefit more if both the caregivers and the management of the hospice were integrated into the study.

As many as nine caregivers postulated their experience of burnout. Results show that six caregivers did not indicate their experience high burnout. In their responses they stated that they do not have time to be emotionally exhausted as their job did not allow this; the organisational behaviour model considers this a coping mechanism (Colquitt, Lepine & Wesson , 2009).

The study also found that except for one caregiver who works 13 hours a day, the other 14 caregivers work 12 hours a day. The length of service in terms of hours might also lead to tiredness and burnout; however, shift work is most common in hospice work which ensures that caregivers and nurses take breaks (Wright, 2004).

Findings also show that some caregivers find it challenging to balance their work and personal lives. According to Boyle (2011): "Work/life balance requires both introspection and action that is ongoing and perceived as necessary to ensure professional longevity."

Objective 2: To measure the level of compassion satisfaction, secondary traumatic stress and burnout as experienced by caregivers at Sparrow Ministries Hospice using the ProQol quality of life scale from Hudnall Stamm, (2009).

Compassion Satisfaction

Eight out of 15 caregivers had high levels of compassion satisfaction while the other seven had an average level of compassion satisfaction. According to Stamm (2009), compassion satisfaction derives from the pleasure of doing work. High scores on the compassion satisfaction scale mean that the caregiver is satisfied with their work and they can also be effective in their role. However for those who scored low or average on the compassion satisfaction scale, it does not necessarily mean they are not happy or satisfied with their job. There might be certain elements about their job that are challenging and as a result pull them down. The organisational behaviour model stresses how some challenging situations at work such as helping a very difficult patient tend to hinder goal attainment and progress.

In this study there were more caregivers who experience compassion satisfaction than those who had average to low compassion satisfaction

Secondary Traumatic Stress

Thirteen participants experienced average levels of secondary traumatic stress and only two experienced low secondary traumatic stress levels. Secondary traumatic stress has to do with work-related experiences of other people‘s traumatic events. According to Stamm (2009), the symptoms of secondary traumatic stress are related to particular events and situations that the caregiver experienced and has left them feeling frightened, having images that keeps appearing in their mind and also avoiding things that might make them re-live those experiences.

Higher scores on the secondary traumatic stress scale might indicate that there are events at work that happened and are still frightening to the caregiver. For example losing a patient is traumatic not only to the patient’s family, but to the caregivers as well. Another example which could have led to high levels of secondary traumatic stress was, fear of being infected with TB due to lack of medication especially on patients who have developed MDR. Findings in the study indicate that

none of the caregivers had experienced high levels of compassion fatigue and secondary traumatic stress.

Burnout

None of the 15 caregivers had experienced high levels of burnout; 11 caregivers experienced average burnout levels and four caregivers experienced low burnout levels. According to Miller (2000) burnout is associated with feelings of helplessness and might lead to feeling incapable of doing the job. The feelings are usually negative and take time to manifest. Such negative feelings might be associated with the workload or difficulty with the work environment. Higher scores on the burnout scale might reflect that the caregiver is at risk of experiencing burnout. According to Stamm (2009) the high scores on the ProQol scale might also be influenced by how a caregiver feels that day; however, if the scores remain high when re-tested, then there is a call for concern.

The research findings show that there was experience of high compassion satisfaction levels but there were no high burnout levels and nor were there high secondary traumatic stress levels. However, it should be noted that the ProQol scale is not a diagnostic tool. Therefore scores from these three scales cannot lead to the researcher making absolute statements about the caregivers' experiences. The results can be utilised as a guideline when dealing with compassion satisfaction, secondary traumatic stress and burnout (Stamm, 2009).

Objective 3: To explore the nature of professional support services offered to caregivers at Sparrow Ministries Hospice in dealing with compassion satisfaction, secondary traumatic stress and burnout.

Findings indicate that caregivers tend to find it challenging to separate their personal lives from their work lives; the stress at work tends to affect their lives outside of work and thus they need some form of support at work.

The caregivers were not aware of any professional support services provided. They usually deal with work challenges and stresses on their own which greatly affects the execution of their work. Lack of professional support services might lead to compassion fatigue and burnout of the caregivers. Support services such as counselling, trauma debriefing and supervision allow the

caregivers to have space where they can deal with their work challenges and avoid suffering from burnout (Clark, 2011).

Findings also indicate the need for professional support services to be offered freely to caregivers working in NPOs offering palliative care to terminally ill patients. NPOs rely mostly on minimal government funding and private donors. It is therefore necessary for such services to be offered free, not only because caregivers cannot afford, but because such services will assist in dealing with compassion fatigue, secondary traumatic stress and burnout. In the end when caregivers are being supported emotionally, they might not run the risk of experiencing burnout and therefore they might become effective caregivers (Stamm, 2009).

5.2 CONCLUSION

Previous research has shown that those who are involved in caring for people that have been exposed to traumatic events are at risks themselves of developing symptoms associated with burnout, compassion fatigue and secondary traumatic stress (Stamm, 2010). In this study it was shown that caregivers as a result of caring for terminally ill patients have experienced both the negative and positive aspects of such work. Both aspects could be attributed to the working conditions and caregiver's own personal challenges such as family and unresolved experiences of own trauma.

Based on such findings, it is suggested that Sparrow Ministries Hospice explores prevention programmes which might help to minimise the negative impact and improve the professional quality of life of the caregivers. However the concept of professional quality of life does not only involve organisations implementing programmes but also individual caregivers taking responsibility for their own self-care.

5.3 RECOMMENDATIONS

Based on the above findings of the study, the following recommendations were made:

Recommendations For The Organisation

- In order to address some of the organisational structures issues presented by the caregivers, it might be useful for the management of the hospice to engage with the caregivers on such issues. For example working hours, shift, stipends, incentives, medication to prevent infections etc.

- The services provided by hospice to terminally ill patients' poses risks of burnout and secondary traumatic stress on caregivers. It would assist the management of the hospice if Employee wellness programmes were to be developed to help caregivers build lifestyles that will enable them to achieve their full physical and emotional potential through mental health awareness. These programmes could also assist in promoting the caregiver's compassion satisfaction and dealing with secondary traumatic stress and burnout.

- Funding remains a challenge for most NPOs, it is therefore suggested that free counselling services be explored and made available to the caregivers in helping them deal with the negative impact of caring for terminally ill patients.

Recommendations For Caregivers

- The caregivers also need to do a lot of self-awareness evaluations in order to monitor how their work might be having an impact on their personal and professional lives.

- The caregivers should equip themselves with knowledge about compassion fatigue, secondary traumatic stress and burnout through attending training and skills workshops.

- There is also a need for peer support groups whereby caregivers can share their challenges regarding their work and together explore coping strategies.

Recommendations For Future Studies

- Due to the small sample size for a mixed methods study, it is recommended that the study be replicated on a larger population of caregivers working with terminally ill patients. A sample of 15 participants was not enough therefore the results of this study could not be generalised.

- To avoid an over focus on clinical or therapeutic responses in relation to compassion satisfaction, secondary traumatic stress and burnout, one should also pay attention to

organisational structures and policies. Incorporate issues such as the working conditions by interviewing both the caregivers and the management of the hospice.

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APPENDICES

APPENDIX A: PARTICIPANT INFORMATION FORM

My name is **Adelaide Mangena** and I am a final year Masters student registered for the Masters Degree in Occupational Social Work at the University of the Witwatersrand. It is a requirement for the Masters programme for me to conduct a research study. I have chosen to interview caregivers at Sparrow Ministries Hospice on their experiences of caring for terminally ill patients. It is hoped that the information gathered from the interviews will raise awareness about secondary traumatic stress, compassion fatigue and burnout in hopefully assisting caregivers in taking care of themselves.

I therefore would like to invite you to be part of the study. The study is totally voluntary, you are not at any point forced to participate. You can also withdraw from the study at any time should you wish to do so. Your unwillingness to participate in the study will not in any form affect your work at Sparrow Ministries Hospice.

I will be using a tape recorder during the interviews, which will be at your consent. As I am still a student, I am required to be under supervision. Only my supervisor and I will have access to the tape. No personal information such as your name will be mentioned in the final research report.

The interview might evoke emotional issues for you during and after the interview. I have arranged with Ms Jennifer Mamabolo to offer debriefing or counselling free of charge should the need arise. You can contact Ms Mamabolo on 0733821344. Should you require more clarity you can contact me on 082 841 4638 or my Supervisor Francine Masson on (011) 717 4480.

Thank you for taking the time to consider being part of the study

Yours sincerely

Adelaide Mangena

APPENDIX B: CONSENT FORM FOR PARTICIPATION IN THE STUDY

I hereby consent to participate in the research project. The purpose and procedure of this study have been explained to me. I understand that my participation is voluntary and that I may chose not to answer any particular items or withdraw from the study at any time without any negative consequences. I understand that my responses will be kept confidential.

NAME OF PARTICIPANT:_____

DATE: _____

SIGNATURE: _____

APPENDIX C: CONSENT FORM FOR AUDIO-TAPING OF THE INTERVIEW

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

NAME OF PARTICIPANT: _____

DATE: _____

SIGNATURE: _____

APPENDIX D: SEMI-STRUCTURED INTERVIEW SCHEDULE

The impact of compassion satisfaction, secondary traumatic stress and burnout on HIV/AIDS care givers at Sparrow Ministries Hospice.

1. Personal details (please tick the correct category)

Gender: _____ Male

_____ Female

Age in years: _____

Race: _____ Black

_____ White

_____ Coloured

_____ Indian

_____ Other (please specify)

Marital status: _____ Single

_____ Married

_____ Divorced

_____ Widowed

_____ Other (please specify)

2. Working experience

How long have you been a care giver? _____

How long have you worked at the hospice? _____

How many hours do you work per day? _____

How many days do you work per week? _____

What training did you receive? _____

3. Burnout, compassion fatigue and compassion satisfaction

Tell me about your work as a care giver at the hospice?

_____

What are your responsibilities as a care giver?

_____

How do you feel about caring for terminally ill HIV/AIDS patients?

_____

What are your thoughts with regards to the treatment of HIV/AIDS?

_____

There is still no cure for HIV/AIDS, how does this affect caring for terminally ill patients?

_____

How do you deal with the loss of a patient at the hospice if it occurs?

_____

It must be difficult for the patient `s family to lose their loved one. How do you help them?

_____

When your working day is over how do you feel about your work?

_____

5. Personal relationships

It must be hard to separate your feelings about work from your personal life. How do you manage?

Who are you currently living with at home?

The people you live with, how do they feel about your work as a care giver?

How do you spend your free time when you are not at work?

---

6. Professional support services for care givers

With whom do you share your challenges of being a care giver with?

At the hospice do feel comfortable to discuss your challenges about work? And with whom do you share those challenges?

How often do you make time to discuss and share your feelings and challenges about your work at the hospice?

What suggestions do you have about your work at the hospice that could make it easier for you to care for the terminally ill patients adequately?

Personally what would you like to change in order to take good care of yourself and still be the best care giver?

THANK YOU FOR YOUR PARTICIPATION.

APPENDIX E: PROFESSIONAL QUALITY OF LIFE SCALE (PROQOL) (2009)

PROFESSIONAL QUALITY OF LIFE SCALE (PROQOL)

COMPASSION SATISFACTION AND COMPASSION FATIGUE
(PROQOL) VERSION 5 (2009)

When you *[help]* people you have direct contact with their lives. As you may have found, your compassion for those you *[help]* can affect you in positive and negative ways. Below are some-questions about your experiences, both positive and negative, as a *[helper]*. Consider each of the following questions about you and your current work situation. Select the number that honestly reflects how frequently you experienced these things in the last 30 days.

1=Never 2=Rarely 3=Sometimes 4=Often 5=Very Often

_____ 1. I am happy.
_____ 2. I am preoccupied with more than one person I *[help]*.
_____ 3. I get satisfaction from being able to *[help]* people.
_____ 4. I feel connected to others.
_____ 5. I jump or am startled by unexpected sounds.
_____ 6. I feel invigorated after working with those I *[help]*.
_____ 7. I find it difficult to separate my personal life from my life as a *[helper]*.
_____ 8. I am not as productive at work because I am losing sleep over traumatic experiences of a person I *[help]*.
_____ 9. I think that I might have been affected by the traumatic stress of those I *[help]*.
_____ 10. I feel trapped by my job as a *[helper]*.
_____ 11. Because of my *[helping]*, I have felt "on edge" about various things.
_____ 12. I like my work as a *[helper]*.
_____ 13. I feel depressed because of the traumatic experiences of the people I *[help]*.
_____ 14. I feel as though I am experiencing the trauma of someone I have *[helped]*.
_____ 15. I have beliefs that sustain me.
_____ 16. I am pleased with how I am able to keep up with *[helping]* techniques and protocols.
_____ 17. I am the person I always wanted to be.
_____ 18. My work makes me feel satisfied.
_____ 19. I feel worn out because of my work as a *[helper]*.
_____ 20. I have happy thoughts and feelings about those I *[help]* and how I could help them.
_____ 21. I feel overwhelmed because my case [work] load seems endless.
_____ 22. I believe I can make a difference through my work.
_____ 23. I avoid certain activities or situations because they remind me of frightening experiences of the people I *[help]*.
_____ 24. I am proud of what I can do to *[help]*.
_____ 25. As a result of my *[helping]*, I have intrusive, frightening thoughts.
_____ 26. I feel "bogged down" by the system.
_____ 27. I have thoughts that I am a "success" as a *[helper]*.
_____ 28. I can't recall important parts of my work with trauma victims.
_____ 29. I am a very caring person.
_____ 30. I am happy that I chose to do this work.

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YOUR SCORES ON THE PROQOL: PROFESSIONAL QUALITY OF LIFE SCREENING

Based on your responses, place your personal scores below. If you have any concerns, you should discuss them with a physical or mental health care professional.

Compassion Satisfaction _____

Compassion satisfaction is about the pleasure you derive from being able to do your work well. For example, you may feel like it is a pleasure to help others through your work. You may feel positively about your colleagues or your ability to contribute to the work setting or even the greater good of society. Higher scores on this scale represent a greater satisfaction related to your ability to be an effective caregiver in your job.

The average score is 50 (SD 10; alpha scale reliability .88). About 25% of people score higher than 57 and about 25% of people score below 43. If you are in the higher range, you probably derive a good deal of professional satisfaction from your position. If your scores are below 40, you may either find problems with your job, or there may be some other reason—for example, you might derive your satisfaction from activities other than your job.

Burnout_____

Most people have an intuitive idea of what burnout is. From the research perspective, burnout is one of the elements of Compassion Fatigue (CF). It is associated with feelings of hopelessness and difficulties in dealing with work or in doing your job effectively. These negative feelings usually have a gradual onset. They can reflect the feeling that your efforts make no difference, or they can be associated with a very high workload or a non-supportive work environment. Higher scores on this scale mean that you are at higher risk for burnout.

The average score on the burnout scale is 50 (SD 10; alpha scale reliability .75). About 25% of people score above 57 and about 25% of people score below 43. If your score is below 43, this probably reflects positive feelings about your ability to be effective in your work. If you score above 57 you may wish to think about what at work makes you feel like you are not effective in your position. Your score may reflect your mood; perhaps you were having a "bad day" or are in need of some time off. If the high score persists or if it is reflective of other worries, it may be a cause for concern.

Secondary Traumatic Stress_____

The second component of Compassion Fatigue (CF) is secondary traumatic stress (STS). It is about your work related, secondary exposure to extremely or traumatically stressful events. Developing problems due to exposure to other's trauma is somewhat rare but does happen to many people who care for those who have experienced extremely or traumatically stressful events. For example, you may repeatedly hear stories about the traumatic things that happen to other people, commonly called Vicarious Traumatization. If your work puts you directly in the path of danger, for example, field work in a war or area of civil violence, this is not secondary exposure; your exposure is primary. However, if you are exposed to others' traumatic events as a result of your work, for example, as a therapist or an emergency worker, this is secondary exposure. The symptoms of STS are usually rapid in onset and associated with a particular event. They may include being afraid, having difficulty sleeping, having images of the upsetting event pop into your mind, or avoiding things that remind you of the event.

The average score on this scale is 50 (SD 10; alpha scale reliability .81). About 25% of people score below 43 and about 25% of people score above 57. If your score is above 57, you may want to take some time to think about what at work may be frightening to you or if there is some other reason for the elevated score. While higher scores do not mean that you do have a problem, they are an indication that you may want to examine how you feel about your work and your work environment. You may wish to discuss this with your supervisor, a colleague, or a health care professional.

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WHAT IS MY SCORE AND WHAT DOES IT MEAN?

In this section, you will score your test so you understand the interpretation for you. To find your score on **each section**, total the questions listed on the left and then find your score in the table on the right of the section.

Compassion Satisfaction Scale

Copy your rating on each of these questions on to this table and add them up. When you have added then up you can find your score on the table to the right.

3. ____
6. ____
12. ____
16. ____
18. ____
20. ____
22. ____
24. ____
27. ____
30. ____

Total: ____

The sum of my Compassion Satisfaction questions is	So My Score Equals	And my Compassion Satisfaction level is
22 or less	43 or less	Low
Between 23 and 41	Around 50	Average
42 or more	57 or more	High

Burnout Scale

On the burnout scale you will need to take an extra step. Starred items are "reverse scored." If you scored the item 1, write a 5 beside it. The reason we ask you to reverse the scores is because scientifically the measure works better when these questions are asked in a positive way though they can tell us more about their negative form. For example, question 1. "I am happy" tells us more about the effects of helping when you are not happy so you reverse the score

You Wrote	Change to
	5
2	4
3	3
4	2
5	1

*1. ____ ▪ ____
*4. ____ ▪ ____
8. ____
10. ____
*15. ____ ▪ ____
*17. ____ ▪ ____
19. ____
21. ____
26. ____
*29. ____ ▪ ____

Total: ____

The sum of my Burnout Questions is	So my score equals	And my Burnout level is
22 or less	43 or less	Low
Between 23 and 41	Around 50	Average
42 or more	57 or more	High

Secondary Traumatic Stress Scale

Just like you did on Compassion Satisfaction, copy your rating on each of these questions on to this table and add them up. When you have added then up you can find your score on the table to the right.

2. ____
5. ____
7. ____
9. ____
11. ____
13. ____
14. ____
23. ____
25. ____
28. ____

Total: ____

The sum of my Secondary Trauma questions is	So My Score Equals	And my Secondary Traumatic Stress level is
22 or less	43 or less	Low
Between 23 and 41	Around 50	Average
42 or more	57 or more	High

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