

**ASSOCIATIONS BETWEEN PERSONAL ATTRIBUTES
AND
COMPASSION FATIGUE,
COMPASSION SATISFACTION AND BURNOUT
AMONG
CAREGIVERS OF PEOPLE LIVING WITH HIV AND AIDS**

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ABSTRACT

Compassion fatigue and burnout have the potential to compromise the ability of caregivers to work effectively, while compassion satisfaction may serve a protective function. This study investigated levels of compassion fatigue, burnout and compassion satisfaction among caregivers, and explored relationships between these and caregivers' personal attributes. Eighty-three caregivers working in the field of HIV and AIDS in the uMngeni Municipality in the Kwa Zulu-Natal midlands completed two self-report questionnaires, the Professional Quality of Life Scale (ProQOL, Stamm, 2009), and another regarding their personal attributes. Respondents showed an overall pattern of relatively high Compassion Satisfaction, average level of Burnout, and a very high level of Secondary Traumatic Stress, a profile usually associated with people working in situations of armed conflict. Compassion Satisfaction was negatively correlated with Burnout and Secondary Traumatic Stress, while Burnout was positively correlated with Secondary Traumatic Stress. Significant effects were found with the following personal attributes: (1) gender; (2) role clarity; (3) perceived efficacy; (4) secondary stigma; (5) social support; (6) personal history of HIV or AIDS; (7) access to counselling or therapy; (8) organisational support; and (9) self-care. Implications of these findings are discussed with reference to sustainable care, intervention and further research.

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DECLARATION

I hereby declare that this dissertation is my own work, and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

Signature

Date:

CHAPTER 1 – INTRODUCTION TO THE STUDY

1.1 Introduction

In South Africa, the public healthcare system is inadequately resourced to provide hospital care for all patients infected with the Human Immunodeficiency Virus (HIV). As a consequence, home-based care has been actively promoted in government policy (Akintola, 2004). Much of the responsibility for caring for those infected rests with volunteer workers from affected communities who are frequently unpaid or receive only basic stipends to cover their expenses (ibid.). In addition to the strain and stresses associated with the work itself, in cases when volunteers themselves are HIV positive, witnessing the disease progression in those they care for can induce anxiety concerning their own health and futures (DeCarlo & Folkman, 1997).

1.2 Theoretical background for the study

1.2.1 Definition of terms

1.2.1.1 Caregivers

The term “caregivers” is a broad one, and in the context of HIV and Acquired Immune Deficiency Syndrome (AIDS), it has been used to describe professional health workers (such as nursing staff), family members, partners and friends of patients, and voluntary community workers (King, 2002). Caring for patients with chronic illnesses can also result in caregivers neglecting their own personal wellbeing in terms of getting sufficient nutrition, sleep, exercise and support (Brown, 2002). Consequently, caregivers may experience reduced capacity to function, loss of perspective and vulnerability to compassion fatigue (Figley, 1995, cited in Brown, 2002). The primary focus of this study was home-based caregivers who render services to clients in their own communities under the auspices of various non-governmental and community-based organisations.

1.2.1.2 Compassion fatigue

Compassion fatigue is also known as secondary traumatic stress (STS) (Deighton, Gurriss & Traue, 2007). It is described as a syndrome which results from empathising with people who have experienced painful or traumatic situations, and has symptoms similar to those of post-traumatic stress disorder (PTSD). This is despite the fact that

the person experiencing them has not been exposed to the traumatic events directly (Figley, 1995, cited in Deighton et al., 2007; Sabo, 2006). The symptoms of compassion fatigue can have a sudden onset, as opposed to the gradual, cumulative progression associated with burnout (ibid.). However, there is potential for faster recovery from compassion fatigue than from burnout, which tends to have a more chronic course (Figley, 1995; Melamed, Shirom & Toker, 2006).

1.2.1.3 Burnout

Burnout is a less specific term than compassion fatigue, and entails symptoms such as emotional exhaustion, a sense of disconnection from other people and a lack of occupational fulfilment (Maslach, 1982, cited in Deighton et al., 2007). Onset is believed to be related to factors of an individual's work environment such as a heavy workload or a great degree of responsibility, a sense of lack of control, and interpersonal problems with co-workers (Maslach & Leiter, 1997).

1.2.1.4 Compassion satisfaction

Compassion satisfaction refers to the sense of personal fulfilment experienced by people who help others (Stamm, 2005b). In this particular context, this may be derived from the knowledge that they have had a positive impact on the lives of clients, the challenge and mental stimulation of working in this field, the respect and gratitude of those they have helped, enhanced personal efficacy and an increased sense of belonging in their communities (Bennett et al., 1994; Maslanka, 1996, both cited in Miller, 2000).

1.2.1.5 Personal attributes

For the purposes of this study, this term was used to refer to factors specific to individual caregivers that could conceivably impact on the psychological sequelae of their work. These included demographic characteristics as well as personal and work-related aspects such as remuneration, experience, secondary stigmatisation and access to resources.

1.2.2 Psychological sequelae of caring for people affected by HIV and AIDS

Research suggests that individual response to work-related stress among those in the HIV and AIDS field depends on multiple variables such as training, social and family factors and work context (Miller, 2000). Work stressors in this context include: (1) Working in a field that is highly affected by social stigma, exposing caregivers to the potential of secondary stigmatisation; (2) emotional involvement and identification with clients who have similar backgrounds and life experiences to those of caregivers; (3) the lack of a cure and the ultimately fatal nature of the illness; (4) the prevalence of HIV infection in the community; (5) fears of exposure to infection (or re-infection) in the course of their work; and (6) repeated exposure to death and dying (van Dis & van Dongen, 1993, cited in Miller, 2000). In research conducted in the United Kingdom (UK), it was found that when caring for patients suffering from AIDS, health professionals exhibited higher levels of anxiety and psychological distress than when caring for patients with similar symptomatology and demographic profiles who were HIV negative (Trieber, Shaw & Malcom, 1987, cited in Miller, 2000). This suggests that work with people with HIV and AIDS poses particular challenges to the well-being and continuing performance of caregivers in the field.

1.3 Motivation for the study

The researcher has spent some time working as a volunteer with a non-governmental organisation (NGO) involved in the HIV and AIDS field. Accompanying community health workers on home visits to clients in poorly-resourced areas made the researcher aware of the highly demanding nature of home-based care, and of the commitment and empathy with which many caregivers approach their work.

Empathy for patients is essential for caregivers to render an effective service; yet this is what makes them vulnerable to compassion fatigue, which in turn may compromise their capacity to care for patients. It was, therefore, important from the perspective of both that factors associated with carers' ability to cope were explored. There is a high attrition rate among volunteers engaged in home-based care in South Africa (Akintola, 2004). However, some caregivers remain working in this challenging field for extended periods. The researcher hopes that this study may prove useful in future

interventions to reduce this attrition rate.

1.4 Significance of the study

In a meta-analysis of variables associated with burnout among psychiatric nurses (Melchior, Bours, Schmitz & Wittich, 1997, cited in Sabin-Farrell & Turpin, 2003), the authors noted the scarcity of research studies that focussed on the particular conditions of the patients with whom these nurses worked. Sabin-Farrell and Turpin (2003) state that this reflects a wider trend among studies of burnout and mental health conditions among healthcare staff, where groupings are generally made according to staff profession or location, rather than the profiles of the people (patients/ clients) who they serve in their work. However, particularly given the research by Trieber et al. (1987, cited in Miller, 2000) mentioned in 1.2.2 above, it would seem that studying the effects of caring work in relation to particular patient profiles is indicated.

Although community-based care programmes are highly reliant on volunteer caregivers, research involving compassion fatigue and burnout among volunteers working in the HIV and AIDS field is scarce (Miller, 2000). It is hoped that the findings of this research would enhance the ability of organisations involved in this field to render appropriate support to caregivers, so that their performance and well-being may be optimised. This would in turn benefit the people who rely on them for care and support.

1.5 Summary

In general, people working in the so-called ‘caring professions’ have been singled out as being at high risk of work-related stress (Smith, Brice, Collins, Matthews & McNamara, 2000, cited in Sabin-Farrell & Turpin, 2003). More specifically, the risk of developing symptoms of psychological distress seems to be further increased when one’s clients/ patients are people who have HIV and AIDS. Compassion fatigue and burnout have the potential to compromise the ability of carers to work effectively; however, not all those involved in caring for those infected and affected by HIV and AIDS ever develop either of these conditions. On the contrary, many experience their

occupations as deeply rewarding and fulfilling (Miller, 2000). This research is an attempt to understand what factors may be associated with these differing reactions to highly demanding work.

CHAPTER 2 – REVIEW OF LITERATURE

2.1 Introduction

This chapter aims to give a broad overview of relevant literature in order to situate the current focus of research within the wider social context against the background of existing theory. Theoretical accounts of compassion fatigue, compassion satisfaction and burnout are discussed and integrated with literature relating to (1) HIV and AIDS in KwaZulu-Natal, (2) care for people living with HIV and AIDS in this context, and (3) caregivers themselves.

2.2 Theories of compassion fatigue, compassion satisfaction and burnout

2.2.1 Compassion fatigue

The term *compassion fatigue* was first used in 1992 to describe the emotional wearing down experienced by nurses as a result of dealing with hospital emergencies on a daily basis (Figley, 2003). However, long before this, concepts encompassing negative consequences of working with traumatised people were described in psychological literature under a variety of other labels (Sabin-Farrell & Turpin, 2003). Among the terms used were secondary traumatic stress (STS), vicarious traumatisation, and countertransference (Stamm, 1997).

Figley (1995) considers compassion fatigue to be an inevitable part of caring for people who have been exposed to trauma. The onset may be sudden and acute, and is often accompanied by feelings of helplessness, confusion, and a sense of isolation from sources of support (Figley, 1995; Rudolph, Stamm & Stamm, 1997).

Compassion fatigue has come to be considered as distinct from countertransference, in part because of the enduring and pervasive nature of the symptoms of compassion fatigue among those affected (Stamm, 1997). While countertransference is usually conceptualised as a phenomenon involving the responses of therapists within the confines of therapeutic relationships, compassion fatigue is associated with broad, “trait-like changes” (Stamm, 1997, p. 1), which carry over into diverse areas of

personal, relational and social functioning in the lives of those affected (Stamm, 1997).

Many writers consider the terms STS and compassion fatigue to be interchangeable (e.g. Deighton et al., 2007; Figley, 1995). However, as noted by Stamm (1997), there is “no consistent or truly satisfying language to describe this phenomenon” (p. 3). In their 2003 review of research in the area, Sabin-Farrell and Turpin elected to define vicarious traumatisation as a broad construct, which “encompasses the concept of secondary traumatisation/ traumatic stress” (p. 451). In contrast, Stamm (1997) initially posits that STS is the broader term, encompassing compassion fatigue, vicarious traumatisation and possibly some instances of countertransference. However in later writing she revises this view, stating that compassion fatigue refers to the negative effects related to working as a helper, and that this can then be further divided into two elements, namely burnout and STS (Stamm, 2009). Deighton et al. (2007) draw a distinction between compassion fatigue and vicarious traumatisation, stating that although they are “very similar concepts” (p. 64), the foci of the two differ in subtle ways. They argue that compassion fatigue is “based on the idea of a syndrome resulting specifically from empathizing with people who are experiencing pain and suffering” (p. 64), while vicarious traumatisation refers to cognitive, relational and affective consequences of “exposure to clients’ material, empathic engagement with clients and a sense of responsibility for them...” (p. 64). However they note in the same article that there is “a large overlap in the symptoms” of compassion fatigue and vicarious traumatisation, and that scales measuring the two may in fact be targeting “different aspects of the same phenomenon” (p. 64). According to Stamm (2009), although there appear to be “nuances” between the terms compassion fatigue, vicarious trauma and secondary traumatic stress, “there is no delineation between them sufficient to say that they are truly different” (p. 9).

In light of this “taxonomical conundrum” (Stamm, 2009, p. 9), for the purposes of this study the terms compassion fatigue, STS and vicarious traumatisation will be considered to be referring to a single phenomenon, in line with the view held by (Bride, Radey & Figley , 2007).

2.2.1.1 Aetiology of Compassion Fatigue

In terms of aetiology, a key feature of compassion fatigue is that it results specifically from working with people who have experienced trauma (Stamm, 1997). This aspect sets it apart from both countertransference and burnout, both of which can develop in the absence of exposure to traumatic content (Stamm, 1997). Factors that can contribute to compassion fatigue include “feelings of professional isolation, large caseloads... frequent contact with traumatized people and visits to trauma environments or locations” (Stamm, Varra, Pearlman & Giller, 2002).

It has been suggested that it is the process of empathic engagement with the traumatised person that makes those who help them vulnerable to compassion fatigue (Figley, 1995; Pearlman & Saakvitne, 1995). A related concept, emotional contagion, has also been implicated in the development of compassion fatigue. Emotional contagion refers to a process which occurs when people reflect and experience the emotional distress and traumatisation they have observed in others. This may happen on a largely unconscious level, in which case these emotions are experienced as though their own, even when they conflict with personal identity and beliefs (Sabin-Farrell & Turpin, 2003).

From a cognitive constructivist perspective, compassion fatigue occurs through the alteration of cognitive schemata which results from working with traumatised people (McCann & Pearlman, 1990, cited in Sabin-Farrell & Turpin, 2003). Cognitive theories suggest that individual experience is mediated by core beliefs and schemata. If an experience corresponds with an existing schema, it is assimilated; if it conflicts, the schema must change to accommodate it (Sabin-Farrell & Turpin, 2003). Similarly, Pearlman and Saakvitne (1995) refer to constructivist self-development theory to explain the origins of compassion fatigue, maintaining that working with traumatised people can cause fundamental shifts in relating to identity and world view, including sense of self and ability to connect with others, capacity for managing emotion, spirituality and sense of meaning, safety, trust, dependency, control and intimacy.

2.2.1.2 Symptoms and sequelae of compassion fatigue

Among social service providers and other ‘helping’ professionals, the symptoms of compassion fatigue have been reported to include feelings of powerlessness,

depression and affective numbness, sleep disturbances and nightmares, autonomic arousal, memory gaps, dissociation, rumination, and intrusive thoughts and images (Smith, 2007; Stamm, Varra, Pearlman & Giller, 2002). Changes in subjectivity may involve altered perceptions of personal safety and feelings of alienation and cynicism (Stamm, Varra, Pearlman & Giller, 2002). In practical terms, compassion fatigue may lead to neglect of self-care, reduced professional effectiveness, more frequent errors, engagement in self-destructive behaviours such as substance abuse, and increases in staff turnover and sick days (Smith, 2007; Stamm, Varra, Pearlman & Giller, 2002). However, in contrast to burnout, compassion fatigue is highly amenable to treatment (Figley, 2002).

2.2.1.3 Compassion fatigue among people working in the HIV and AIDS field

Compassion fatigue among people in human service professions has been described as “widespread” Stamm, Varra, Pearlman and Giller (2002), and research indicates high levels of stress, burnout and compassion fatigue among people working in palliative care environments (Houghton & Christensen, 2006). However, Smith (2007) reports a remarkable gap in research published subsequent to 1997 focussing specifically on compassion fatigue among people working in the field of HIV and AIDS – the sum total found in literature searches consisted of two unpublished dissertations – and adds that the lack of recent published research does not necessarily indicate that compassion fatigue is not a concern in this population; in fact, it may represent a “significant issue” (Smith, 2007, p. 193). In the nursing field, it has been noted that levels of burnout and compassion fatigue have risen dramatically in the presence of the HIV/ AIDS epidemic. Additionally, whereas previously it was predominantly veteran nurses worn down by years of service who were affected, compassion fatigue is now frequently being observed among nurses in the early years of their careers (King, 2002).

2.2.2 Compassion satisfaction

Compassion satisfaction is a term that describes the positive effects that can result from being able to help others; the “pleasure derived from working well” (Deighton et al., 2007; Stamm, Varra, Pearlman & Giller, 2002). Specifically, these effects have

been said to include (1) enhanced sense of personal meaning, derived from workers' belief that they are making a positive contribution in the alleviation of a social problem; (2) increased sensitivity to and empathy for those that they work with, resulting in a deeper sense of connectedness; (3) enhanced self-esteem; (4) renewed hope and belief in human resilience; and (5) a more integrated and balanced understanding of humanity, resulting from exposure to both hurtful and healing images (McCann & Pearlman, 1990).

Some of the sources of satisfaction detailed above are echoed in local research findings. Among South African community caregivers, it is reported that sources of reward included feelings of satisfaction derived from helping clients, and the belief that they were making a positive contribution to their communities (Uys, 2002). South African HIV counsellors identified some of the rewards of their work as the intellectual stimulation and challenge they themselves derived from their work; the appreciation shown by their clients and members of the wider community; and feeling that they are able to make a difference in the lives of their clients (Richter, Durrheim, Griesel & Solomon, 1999).

Farber (2000) suggests that such satisfaction may act as a mediator of the stressors associated with this field of work. This seems to be supported by an empirical research finding that counsellors identified the emotional rewards of knowing they are helping people affected by HIV/ AIDS acted as an important source of sustenance to continue in their work (Richter et al., 1999). However, Farber (2000) cautions that when the satisfaction derived from work is not sufficient to balance the stressors and is perceived to be incommensurate with the demands made of workers, the results may be emotional and physical distress, ceasing to care, loss of motivation to work hard, and ultimately burnout (Farber, 2000).

2.2.3 Burnout

Burnout has been defined as “a state of physical, emotional and mental exhaustion caused by long term involvement in emotionally demanding situations” (Pines & Aronson, 1988, p.9, cited in Figley, 1995). Since the term was first coined by Freudenberg in 1974, it has been the subject of considerable research, and it

“continues to be studied empirically, described theoretically, and discussed extensively by mental-health professionals and the general public” (Farber, 2000, p. 589; Figley 1995). Burnout is not yet included in the American Psychiatric Association's *Diagnostic and statistical manual of mental disorders* (DSM). However in the tenth revision of its *International classification of diseases and related health problems* (ICD-10), the World Health Organisation lists burnout as “a state of vital exhaustion” in the chapter of factors influencing health status and contact with health services (World Health Organisation, 2007).

Although much of the literature in recent years focuses on burnout in corporate settings, most early descriptions of burnout were of a phenomenon affecting people working in the human-services (Farber, 2000). Burnout in this context is defined as a problem of perceived “inconsequentiality”, where the workers feel that (1) they have been unable to make an appreciable difference in the lives of people they have been seeking to help, (2) there is no end to the work they are attempting to accomplish, and (3) their work is personally unrewarding. From the above description, it would seem that perceptions associated with burnout are the negation of those linked to compassion satisfaction, and therefore that among individuals high levels of burnout would be associated with low levels of compassion satisfaction, and vice versa (i.e. that the two would be negatively correlated).

2.2.3.1 Symptoms and sequelae of burnout

People seeking therapy presenting with burnout report a range of complaints, including feeling overburdened by their work; irritability, cynicism and disillusionment; interpersonal difficulties (including in family relationships); profound exhaustion; and the perception that they are powerless to improve their situations (Farber, 2000). Kahill (1988, cited in Figley, 1995) grouped the symptoms of burnout into the following five categories (1) physical symptoms, such as fatigue, somatic complaints and sleeping problems; (2) emotional symptoms, for example guilt, anxiety, and feelings of helplessness; (3) behavioural symptoms, such as cynicism, substance abuse, aggression and callousness; (4) work-related symptoms, such as absenteeism, habitual lateness, decline in performance and resignation; and (5) interpersonal problems, for example impaired communication and relating with clients and colleagues, or dehumanising or intellectualising clients.

According to Maslach and Leiter (1997), although individual people may experience burnout differently, there are some key universals, namely (1) erosion of engagement, (2) erosion of emotion, and (3) imbalance of fit between the people and their work. These are defined as follows:

(1) Erosion of engagement: This is experienced as an increasing sense that work is no longer fulfilling, interesting or meaningful.

(2) Erosion of emotion: The positive emotions that may have previously been associated with work become displaced by “anger, anxiety and depression” (p. 23).

(3) Imbalance of fit: This is experienced as a gradual but increasing incongruence between the needs of individual workers and the demands of their work. This is represented as a reciprocal process between people and their work environments, where each negatively impacts on the other in a cycle of negativity (Maslach & Leiter, 1997).

It has been reported that work-related burnout can have serious implications for physical as well as mental health. Recent research indicates that burnout may constitute as serious a risk factor for the development of cardiovascular disease as other well-documented risk factors such as smoking and elevated body mass index (Melamed, Shirom & Toker, 2006). It is suggested that this risk may be linked to lower levels of cortisol, an important immune system regulating hormone, among people with burnout. The authors further speculate that the chronic course of burnout is related to a reciprocal process between its symptoms and physiological processes, which, once established, can be very hard to break (ibid.).

2.2.3.2 Burnout among people working in the HIV and AIDS field

“More must be done to prevent burnout among caregivers and help them deal with the stress, grief and trauma associated with caring.” (United Nations Secretary-General's Task Force on Women, Girls and HIV/AIDS in Southern Africa, 2004, p. 41).

According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), burnout has long been identified as a crucial issue in HIV care and support, and an empirical

evaluation of South African HIV/AIDS counselling suggests that burnout is both prevalent and problematic among local workers in this field (Richter, Durrheim, Griesel & Solomon, 1999; UNAIDS, 2008). High levels of stress and burnout among counsellors were noted, and these were identified as factors which limited the effectiveness of interventions (Richter et al., 1999). It seems probable that if there are also high levels of burnout among home-based carers, their ability to positively intervene could be similarly compromised.

2.2.3.3 Aetiology of burnout

From a social learning perspective, McCann and Pearlman (1990) contend that burnout can be understood as the result of personal goals in excess of what can realistically be accomplished, which are maintained by an individual despite situational feedback suggesting that these are impossible to attain.

Adding a further dimension to the above explanation, Pines (2000) contributes a psychodynamic existential perspective on the aetiology of burnout. She maintains that occupation may function as a way of giving a sense of meaning in the lives of workers, and – on an unconscious level – as a means of resolving early issues. As a result, people tend to approach their work with high levels of motivation and strong expectations. In such cases, occupational success leads to an increased sense of meaningfulness, and to some resolution of the hurt caused by unmet early needs. Conversely, however, the perception of occupational failure means that the search for existential meaning is unfulfilled, hopes and expectations are unmet, and the early wounds in the unconscious remain unresolved. According to Pines, burnout is the result of this second scenario.

It should be noted that the above formulation rests on the assumption that people need to feel that their occupation is worthwhile and that they can make a “significant contribution” (Pines, 2000, p. 641) through their work. From a South African perspective, however, one could make the argument that seeking existential meaning in one’s work is something of a luxury. In the context of the high rates of unemployment and poverty currently present in society, one might expect that most workers would be more concerned about feeding their families than finding meaning in their occupations. However, given that most HIV and AIDS care programmes rely

on unpaid volunteers (Akintola, 2004), it seems that many of those working in this field are indeed motivated by factors other than material reward.

From a psychosocial perspective, burnout is seen as resulting from the interaction of the personality characteristics of particular individuals with external stressors arising from their organisational and societal contexts (Farber, 2000). Thus it seems that the phenomenon of burnout is necessarily contextually-embedded; that is, it is defined by the prevailing values and motives of the context as well as those who experience it. By way of example, Farber (2000) notes that in North America, the predominant cultural value in the late 1960s and early 1970s (when burnout was first described) was idealism. By the turn of the millennium, however, this had been supplanted by more materialistic and self-orientated motivations. One might therefore anticipate that a comprehensive understanding of the aetiology of burnout in a local context would require an appreciation of the prevailing societal pressures. A full explication of these would however be beyond the scope of the present study.

2.3 HIV and AIDS in KwaZulu-Natal

The African continent is home to an estimated 88% of people living with HIV and AIDS (UNAIDS, 2008). South Africa is reportedly the country with the largest number of HIV-positive people in the world – more than 5 million – and within this context, KwaZulu-Natal is one of the most severely affected provinces, with an estimated prevalence of 15,8% among people over the age of two years (Demmer, 2006; Shisana et al., 2009). The high prevalence of HIV infection in KwaZulu-Natal has been linked to various factors. Among these are (1) the political conflict and the resultant social upheaval of the 1980s and early 1990s; (2) the large proportion of migrant workers in the population; and (3) the province's geographical situation, being the location of one of the continent's busiest harbours and a major thoroughfare for transporting goods by road (Armstrong, 2000). These factors are briefly explained below as follows:

(1) Political conflict: KwaZulu-Natal in the 1980s and 1990s was marked by ongoing political violence which led to the deaths of up to 20 000 people (Taylor, 2001, cited in Injobo Nebandla, 2005). Considerable social upheaval resulted from the province

becoming increasingly divided geographically along lines of perceived political allegiance. Tens of thousands of people became displaced as they fled the violent attacks which targeted areas perceived as “belonging” to political opponents (Injobo Nebandla, 2005). This conflict was so severe that commentators at the time referred to “all out war” (Provincial TRC Report, 1998, cited in Injobo Nebandla, 2005).

The relationship between conflict and HIV prevalence is not entirely clear. Although it has frequently been suggested that the rate of transmission increases in displaced and conflict-affected populations, a review of published research suggests that there is insufficient data to support this contention (Spiegel et al., 2007). Interestingly, it is suggested that the period of social reconstruction after conflict ends may represent a more vulnerable time for high rates of HIV transmission than during the unrest itself (Spiegel et al., 2007). Mechanisms that are suggested to influence this include increased access to transport and increased migration to urban areas (ibid.). From a chronological perspective, the period following the ending of widespread violence in KZN did indeed coincide with a marked increase in the incidence of HIV in the region; however in the absence of supporting data it would be premature to conclude that this was a causal factor in this particular context.

(2) Migrant workers: The pattern of large scale migrant labour in South Africa can in part be traced to the policies of the apartheid-era government, which sought to ensure a steady supply of labour for the mining industry while also maintaining racial separation (Lurie et al., 2003). As a result of these policies, a phenomenon known as “circular” or “oscillating” migration became commonplace: men from rural areas travel to work on the mines in urban centres where they live in single-sex hostels, only returning to their partners and families in the rural areas periodically (Lurie et al., 2003). Migrant workers have historically been an important vector for the spread of HIV infection, and it has been reported that the prevalence of HIV infection among male migrant workers from rural areas in KwaZulu-Natal is significantly higher than among their non-migrant peers – 25,9% compared to 12,7% (Lurie et al., 2003).

(3) Geographical situation: The relevance of the province’s geographical situation as a major thoroughfare for road transport to the HIV prevalence rate is illustrated in part by research conducted among truck drivers in KwaZulu-Natal. Among the findings

were a high overall prevalence of HIV infection - 56% overall – and high-risk sexual behaviour, such as having multiple partners and low rates of condom usage (Ramjee & Gouws, 2002). Additionally, the rapid development of the transport infrastructure in recent years has facilitated much greater freedom of movement for people as well as goods, and consequently also the spread of HIV (Quinn, 1985, cited in Lurie et al., 2003).

2.4 Challenges of caring for people infected and affected by HIV and AIDS

Although most forms of caregiving work can be linked to psychological distress, caring for those with HIV and AIDS presents its own particular challenges and sources of distress (Demmer, 2006). In addition to those factors discussed in the previous chapter (see 1.2.2), these may stem from the nature of the illness itself and a lack of social support (Demmer, 2006).

Witnessing the course and progression of HIV and AIDS can itself be traumatic for caregivers. Opportunistic infections are common owing to the weakened immune systems of people infected, and the physical wasting associated with AIDS transforms the former appearance of patients (Worden, 2009). This may make being with people in an advanced state of illness distressing, to the point that even their loved ones may avoid spending time with them (Worden, 2009).

2.4.1.1 Links between HIV and AIDS and psychopathology

A non-profit organisation providing mental health services to people living with HIV in the US found that their clients often presented with concurrent psychosocial and medical problems (Smith, 2007). Examples of psychopathology among service users included mood and anxiety disorders, panic attacks, dementia, sexual dysfunction, personality disorders, and – in the majority of cases – substance abuse (Smith, 2007). Many clients were also found to have a history of trauma and abuse (Smith, 2007). Similarly, Cournos and Collins (2003) list a variety of mental health problems seen among patients with HIV and AIDS in the US, including substance use, anxiety disorders, mood disorders, psychotic illnesses, sleep disturbances and neuropsychiatric disorders.

The patterns reported above could conceivably be viewed purely as a reflection of the North American context of HIV and AIDS. For example, intravenous drug use has historically been a prominent mode of HIV transmission in the US (Centers for Disease Control and Prevention, 2002), and consequently one might expect people with substance abuse problems to be over-represented among those infected. However, research has shown that various neurological complications are routinely associated with the progression of AIDS. In autopsy studies, evidence of central nervous system (CNS) damage was found in up to 80 percent of cases (Worden, 2009). The effects of CNS damage vary from patient to patient, depending on the brain areas affected; however typically the degree of impairment is quite severe, with symptoms frequently resembling the dysfunctions associated with Alzheimer's disease. As dementia progresses, the premorbid personality of the affected person becomes eclipsed (Worden, 2009). Coupled with the physical wasting mentioned above, this means that families and caregivers of people living with AIDS (PLWA) may have to grieve the loss of the patient before they are physically dead (Worden, 2009). Also, previously cooperative people might become difficult to manage, therefore presenting particular challenges for caregivers.

In addition to the cognitive impairment and dementia resulting specifically from disease progression, there are several other links between HIV/AIDS and psychopathology. Mental health problems tend to be over-represented among people with HIV because of links between mental illness or substance abuse and HIV-related risk behaviours (Cournos & Collins, 2003; Freeman, Patel, Collins & Bertolote, 2005). Also, some antiretroviral drugs have been documented to have psychiatric side-effects, and the psychosocial stressors associated with infection are also a factor in the prevalence of depression and anxiety among people with HIV (Freeman et al., 2005).

Locally, it has been noted that "links between mental health and HIV/AIDS are both profound and highly neglected" (Freeman, 2003, p.60). In South Africa the prevalence of psychopathology in the general population has been reported as 16, 5%, whereas among people with HIV prevalence of mental disorders was 43, 7% (Bodibe, 2010). Among South Africans living with HIV and AIDS, 42% reported feeling depressed in the last year, compared to 29% among those who were not infected

(Shisana et al., 2005, cited in Simbayi et al., 2007). As far back as 2002, doctors at the outpatients department at Durban's King Edward VIII Hospital reported seeing several cases of patients with HIV-related psychosis each day (Cullinan, 2002), and a local study identified AIDS dementia, alcohol abuse, and disorders involving psychosis and anxiety among the clients of home-based carers (Uys, 2002). These links between mental health problems and HIV and AIDS clearly pose additional challenges to caregivers.

2.4.1.2 Limitations in community support

In addition to the devastating symptoms that many patients experience, the terminal phase of AIDS can drag out for an extended period (Demmer, 2006). In South Africa, research has shown that people with AIDS were chronically ill for an average of a year before they died (Steinberg et al., 2002). Although communities may initially provide considerable support and assistance to sick people and their families, this tends to dwindle when the illness is of a protracted nature (Thomas, 2006). This is in part because community members have their own obligations to meet, but in the case of people infected by HIV and AIDS may also reflect the increasing degree of stigmatisation experienced as the infected person's illness progresses (Thomas, 2006). In addition, the family of an infected person may feel compelled to conceal their illness from the community as far as they are able out of fear of incurring stigmatisation and judgement (Demmer, 2006). A further factor that may have a negative impact on community assistance is the perception that those infected will not have the ability to reciprocate in future, and therefore energy expended in helping them is poorly spent (Thomas, 2006). As a consequence, much of the responsibility for the sick is carried by family and community caregivers working "in isolation in private homes" (Thabethe, 2006, p. 104).

2.5 Caregivers

2.5.1 Home-based carers

The first programmes offering home-based care to people with HIV and AIDS originated Europe and North America. Motivation for these programmes was two-fold: to reduce the expense associated with regular hospitalisation, and to provide assistance to families and other carers who were finding it difficult to cope with the

challenges of caring for those who had become ill (Spier & Edwards, 1990, cited in Uys, 2002). Since home-based care was introduced to African countries in the late 1980s and early 1990s, it has become integral to the provision of healthcare for HIV-positive people (Uys, 2002). In the South African context, it has been noted that volunteer home-based careworkers form the “backbone” of community care for people living with HIV and AIDS; however despite the value of this service, it is not unusual for them to receive neither stipends nor incentives (Armstrong, 2000; United Nations Secretary-General's Task Force on Women, Girls and HIV/AIDS in Southern Africa, 2004). Although volunteers are responsible for much of the care for people with HIV/AIDS in both rural and urban areas of Southern Africa, they are often considered to be of low status. This has resulted in them being discriminated against by paid staff of the non-governmental or community-based organisations for whom they work, and by members of the formal healthcare services (United Nations Secretary-General's Task Force on Women, Girls and HIV/AIDS in Southern Africa, 2004; Uys, 2002).

2.5.2 Gender and caring for people living with HIV and AIDS

Caregiving in this context seems inextricably linked to issues of gender. Research indicates that 68% of household caregivers of people with AIDS related illnesses in South Africa are women and girls (Steinberg et al., 2002). In a study investigating the psychosocial impacts on caregivers of people living with AIDS, 43 out of 45 respondents were women (Orner, 2006). This imbalance has been attributed in part to gender inequalities stemming from the traditional roles of women and the gendered division of labour (Akintola, 2004; Mathambo & Richter, 2007).

It seems that this gendered pattern of caregiving responsibility is also reflected in the demographic profile of home-based carers – literature regarding community HIV and AIDS care and support programmes in South Africa notes that caregivers in this setting are predominantly women (Armstrong, 2000; Akintola, 2004; Mathambo & Richter, 2007; Russell & Schneider, 2000, cited in Orner, 2006). In a large study conducted into the practices of South African home-based caregivers over seven different sites, it was found that all the caregivers were women and only one was a man (Uys, 2002).

The policy of promoting community-based care therefore means that the main responsibility for caring for people living with HIV and AIDS continues to be borne by women (Marais, 2006). It has been pointed out that many of these women carry the double burden of caring for members of their own households as well as providing care and support within the wider community (Mathambo & Richter, 2007). Additionally, women – particularly those in poorer communities with high rates of unemployment – typically have less access to social and material resources than their male counterparts (Mathambo & Richter, 2007). This situation has led one analyst to describe home-based care, as it is currently practised, as promoting the “rampant exploitation of women’s labour, financial and emotional reserves” (Marais, 2006, p. 9).

However, it seems that the pattern noted above is not equally true on all levels of non-governmental and community-based organisations involved in HIV and AIDS care, as most of the paid and executive positions within these organisations tend to be occupied by men (United Nations Secretary-General's Task Force on Women, Girls and HIV/AIDS in Southern Africa, 2004). This can be attributed to the patriarchal nature of society, which means that men tend to occupy positions of power and authority within communities (Mathambo & Richter, 2007).

2.5.3 Poverty and resources

Home-based care appears to be a more “realistic” or “affordable” option because its true costs are hidden, deflected back into the domestic zones of the poor. In doing so, it adheres to the same polarising logic that defines our society (Marais, 2006, p. 13).

In unpublished research among volunteers working in community projects in peri-urban areas of KwaZulu-Natal, it was found that a prominent motivation for volunteering was to acquire skills, knowledge and understanding of their field (Gothan, 2003). In many cases volunteers perceive their work as an opportunity for training which would increase their chances of securing formal, paid employment in the future (Armstrong, 2000; Gothan, 2003). This finding was echoed in research conducted in Mpophomeni, a peri-urban township approximately 10 kilometres

outside Howick in the KwaZulu-Natal midlands, where it was found that the women community home-based care workers' hopes that their work would enhance their employability provided them with a motivation to continue their work in the face of considerable hardships (Thabethe, 2006).

In research into community caregivers trained by the South African Hospice Association, Uys (2002) found that caregivers were generally recruited from among the many unemployed people within affected communities, and were paid a stipend for the service they provided. In this study, which was conducted across seven sites, some caregivers did secure formal employment after working in the programme for some time, and Uys suggests that this may have been facilitated by the training and experience they had gained as caregivers (Uys, 2002).

However, Thabethe (2006) asserts that it is false to assume that volunteer caregivers are empowered through their work, and that on the contrary caregivers frequently experience a lack of power and access to resources. Community home-based caregivers are described as predominantly female, Black, and "poor or very poor" (Thabethe, 2006, p. 106). Of the 10 participants in the study Thabethe conducted (aged between 22 and 44), seven had left school before completion because of economic hardship, eight had never been employed, and the remaining two had previously been domestic workers (Thabethe, 2006).

Thabethe argues that in a bid to reduce costs and relieve the pressure on the public healthcare system, policy has effectively shifted the burden of care to communities who cannot afford it (Thabethe, 2006). The resultant situation is conceptualised as one of social power imbalance, where the privileged have access to hospital care and the poor are compelled to die at home in poverty (Thabethe, 2006).

It might be problematic to assume that Thabethe's findings can be generalised as applying to all caregivers, as the study was conducted in a single setting and a small sample size. However, a policy brief on home-based caregiving reports that many volunteer caregivers experience economic stress as a result of unemployment and poor socio-economic conditions (Akintola, 2004). Poor communities in South Africa are the most vulnerable to HIV and AIDS, and home-based care workers are generally

drawn from the communities that they serve (Akintola, 2004; Steinberg et al., 2002).

2.5.4 Roles of caregivers

The following are some of the services that are provided by home-based careworkers in the course of their work:

- 1) Home visits and palliative care (discussed further below)
- 2) Pre- and post-test counselling
- 3) Provision of health education to the community
- 4) Community mobilisation
- 5) Bereavement counselling
- 6) Facilitation of family meetings to plan for the future of children of terminally ill clients
- 7) Partner counselling
- 8) Assistance with household chores (e.g. cooking and cleaning)
- 9) Assistance with childcare
- 10) Help with shopping
- 11) Fetching medication for clients
- 12) Assistance with childcare
- 13) Assisting families with poverty alleviation (food gardening etc.)
- 14) Mediation and conflict resolution within households
- 15) Educating household members regarding symptoms, care, and treatment
- 16) Condom distribution
- 17) Arranging burial of deceased clients
- 18) Delivering supplies for household care (rubber gloves, plastic sheets, etc.)
- 19) Provision of supplementary medications not supplied in clinics (e.g. multivitamins)
- 20) Giving advice regarding home remedies

(Akintola, 2004; Armstrong, 2000; Orner, 2006; Thabethe, 2006; Uys, 2002)

Direct care rendered by community-based carers to their clients includes the provision of counselling, information and psychosocial support (including assistance with disclosure, dealing with stigma and bereavement), symptom control, assistance in

applying for social grants, non-specified assistance such as provision of food parcels, hygiene care and wound care, monitoring adherence to medication and treatment, and accompanying clients to hospitals or clinics (Thabethe, 2006; Uys, 2002). Even relatively symptom-free clients are reported to have a substantial need for support in terms of counselling, health education and welfare intervention. For example, in the home visits observed as part of the study conducted by Uys (2002), a key part of the assistance that caregivers provided related to matters such as grant applications and guardianship issues. Community-based carers also help to lighten the load borne by the family members of clients, who report that their visits are an important source of relief and emotional support (Orner, 2006).

Given the wide variety of functions served by caregivers, it may be worth asking whether the training provided is sufficiently broad to prepare them for the demands to which they are exposed. Empirical research has shown that training that workers perceive as insufficient to cope with the demands of the work with which they are faced, inadequate resources, and role ambiguity are all sources of risk for burnout and compassion fatigue (Deighton et al., 2007; Miller, 2000; Moodley, 2001; Richter et al., 1999; Staines, 2000).

In recent unpublished study, it was found that there was a mismatch between the training community home based caregivers had received and the work that they found was required of them (Thabethe, 2006). In this case, training had focussed chiefly on physical aspects of caring for the sick, neglecting to address other skills relevant to the variety of demands faced by caregivers in communities (Thabethe, 2006). For example, no attention had been given to basic counselling skills, or to aspects of caregiver empowerment such as self-care strategies (Thabethe, 2006). The author of the above study contends that this incongruence between training and work demands has hindered caregivers in their attempts to serve their clients (Thabethe, 2006). Given the focus of the current study, an added concern is how this mismatch would place the caregivers at an increased risk for compassion fatigue and burnout.

2.6 Sources of vulnerability for caregivers

2.6.1 Overload and lack of resources

Overwork is considered a root cause of much work-related distress in many AIDS care contexts, including South Africa (Armstrong, 2000). The tendency for carers to overextend themselves is in some cases motivated by organisational factors – such as demanding supervisors – but can also originate from the carers themselves, as they attempt to respond to overwhelming need in the communities in which they work (Armstrong, 2000). Exacerbating the strain is the lack of clear policy guidelines regarding the roles of home-based carers (Thabethe, 2006).

Steinberg et al. (2002) point out that poor South Africans are the most affected by HIV, and that “in already poor households HIV/AIDS is the tipping point from poverty into destitution” (p. 7). In a qualitative study conducted in Mpophomeni, Thabethe (2006) found that volunteer home-based carers face demands that frequently seem overwhelming, particularly in the context of widespread poverty and lack of resources. This finding seems to accurately reflect the experience of other caregivers working in different areas throughout the country, as exemplified by the following quotes:

Before you can even think of terminal care you are faced with a patient who comes in here with no resources whatsoever... The patient is hungry in front of you. The baby does not even have milk.

- A community caregiver working under the auspices of the South African Hospice Association (Uys, 2002, p. 101)

I thought I was going to give health care, but then you find there's no food in the house, the whole family is hungry, there's no money coming in, and you feel you can do so little.

- A volunteer home-based carer in a rural area of South Africa (Armstrong, 2000, p. 8).

Often the carers themselves lack the resources to do their work effectively, citing shortages of money for transport, materials for record-keeping, and basic medical supplies such as rubber gloves (Armstrong, 2000). Similarly, interviews with

counsellors working in the HIV and AIDS field revealed that they identified their main work stressors as lack of material resources, including transport; and a lack of referral and support networks (Richter, Durrheim, Griesel & Solomon, 1999).

As detailed above, the satisfaction derived from feeling that they are making a positive contribution can serve as an important protective factor for workers. But if they find themselves inadequately resourced to do so in the face of overwhelming need, it seems unlikely that they would be able to find satisfaction in their work, meaning that they are more vulnerable to stress, burnout and compassion fatigue.

2.6.2 Insufficient self-care

In an article on compassion fatigue and mental health service providers working with people living with HIV and AIDS, Smith (2007) states that in many cases the traumatic experiences of people infected by HIV can threaten to overwhelm the self-care strategies of trained professionals.

Training programmes for caregivers may neglect the area of self-care (Thabethe, 2006). Funders, too, may contribute to carers' failure to renew their own inner resources. Armstrong (2000) cites the example of a Ugandan organisation that was forced to discontinue its programme of retreats for counsellors and care-workers because these were considered "an unjustifiable expense" (p. 31). A senior staff member of the organisation commented that the donors evaluated their expenditure solely in terms of how many clients were reached, neglecting to take cognizance of the welfare of those tasked with the practical implementation of care (Armstrong, 2000).

2.6.3 Personal factors

Deighton et al. (2007) cite research studies focussing on trauma therapists which demonstrate a clear link between personal history of trauma and increased risk of developing conditions related to work stress, including burnout and compassion fatigue. This finding builds on an earlier study which found that therapists with personal histories of trauma had more difficulties dealing with client material than

those who did not (Pearlman & McIan, 1995, cited in Stamm, 1997). In the context of the present research, frequently volunteers affiliated with HIV/AIDS home-based care programmes are also caring for sick members of their own households in addition to their roles as carers in the homes of others. In other cases they are themselves infected, and may be registered as clients of the organisation for which they work (Armstrong, 2000; Mathambo & Richter 2007). In cases when volunteers themselves are HIV positive, witnessing the disease progression in those they care for can induce anxiety concerning their own health and futures (DeCarlo & Folkman, 1997). Drawing a parallel with the trauma therapists, it therefore seems plausible to suggest that personal connections to HIV and AIDS illness outside of their work context similarly increases vulnerability for caregivers working in this field.

2.6.4 Stigma

Stigma is defined as a “process of devaluation” in which attributes of the stigmatised person are regarded as “discreditable or unworthy”, which then results in the person being marginalised or regarded as tainted (Goffman, 1964, quoted in Thomas, 2006, p. 3175). Stigma may involve verbal abuse, social isolation and gossip, and can range from relatively subtle manifestations to more extreme, even violent forms (Thomas, 2006).

Research has outlined the existence of three differing types of stigma related to HIV and AIDS, namely (1) self stigma, an internal process characterised by self blame and devaluation; (2) perceived stigma, relating to individuals' fear that they will be stigmatised if they reveal their HIV status; and (3) enacted stigma, which refers to actual discrimination directed against people on the basis of known or perceived HIV status (Bond, Chase & Aggleton, 2002, cited in Thomas, 2006).

Perceived stigma is often a reason that people are unwilling to disclose the cause of their ill-health, and the resulting secrecy adds to the caregivers' burden in a number of ways. In some cases, clients do not wish to disclose their status to the family members, and consequently their caregivers bear the responsibility alone, as they are unable to pass on knowledge or health care skills to other members of the household, or to prepare them to deal with possible complications and deterioration (Armstrong,

2000). They also find themselves forced to conceal the true nature of their clients' illness (ibid.).

A violent and well-publicised example of enacted stigma was the 1998 murder of Gugu Dlamini in a township outside Durban, after she publicly disclosed that she was HIV-positive (Cullinan, 1999). Despite the current high prevalence of HIV infection, there is still a considerable amount of stigma attached to HIV and AIDS in South Africa (Demmer, 2006). Large scale surveys indicated that 40% of people infected with HIV have encountered discrimination as a result of their status, with 20% reporting that they had lost either their employment or accommodation (Simbayi et al., 2007). This stigmatisation has led to AIDS-related deaths being viewed as what Worden (2009) refers to as “socially unspeakable losses”, with the consequence that the death is often attributed to other causes such as cancer (Worden, 2009). Even at funerals, a conspiracy of silence and denial about the true cause of death of the deceased may be maintained (Demmer, 2006). While this secrecy may serve a protective function in terms of AIDS-related stigma, it can expose survivors to emotional distress stemming from fear of exposure of their deception, or guilt and anger at having resorted to this course of action (Worden, 2009).

Even when there is openness about the cause of death, funerals may be occasions where stigma is reinforced rather than challenged. Demmer (2006) cites instances of religious figures using such funerals to warn the congregants against the consequences of an immoral lifestyle, which thereby perpetuates the link between HIV and AIDS and shaming and disgrace in the minds of the community.

In the context of these high levels of enacted stigma, home-based carers may find themselves stigmatised by association – a process known as *social contagion* (Horsman & Sheeran, 1995, cited in Miller, 2000) or secondary stigma (Armstrong, 2000; Miller, 2000). One study reported that volunteer caregivers rendering home-based palliative care were viewed with suspicion by community members, who believed that their visits precipitated death (Demmer, 2006). This perception was grounded in the observation that clients frequently died shortly after the volunteers came to see them (ibid.). A possible explanation for this can be found in anecdotal reports from local caregivers that some families resist calling for help from outside as

long as possible, for fear of stigmatisation by the community. In such cases, by the time a caregiver visits, the client is in advanced stages of illness and frequently close to death.

Home-based carers report that their work exposes them to high levels of stigma within the community, and this has been identified as a factor which adds to their distress (Orner, 2006; Thabethe, 2006). For example, a recent qualitative study in Mpophomeni found that community volunteers who worked with children affected by HIV and AIDS were sometimes subjected to ridicule, name-calling, and some degree of social ostracism as a result of their work (Mathambo & Richter, 2007). In view of this, it seems probable that high levels of stigmatisation would be associated with elevated levels of compassion fatigue and burnout among carers.

2.7 Possible mediating factors

Drawing from literature on burnout and compassion fatigue in various human service fields, it is possible to identify a number of factors which may play a part in protecting people from the negative sequelae of caring work. These factors can be grouped into three broad categories: (1) factors related to the work itself, (2) characteristics of the organisational environment, and (3) factors related to the workers as individuals. Examples of each category are discussed below.

2.7.1 Work-related mediating factors

2.7.1.1 Role clarity

A key factor that appears to influence caregivers' vulnerability is the degree to which their roles are clearly defined. Explicit delineation of caregivers' roles can be protective by ensuring that expectations of both caregivers and clients are appropriate and realistic (Miller, 2000). A clear understanding of the limits of one's responsibilities to clients can also enhance sense of achievement in one's work, which is a factor that protects against compassion stress and burnout (Figley, 2002; Miller, 2000; Moodley, 2001).

2.7.1.2 Realistic targets

Closely related to role clarity is the degree to which the work targets caregivers set for themselves are realistic and achievable, given their circumstances and available resources. Setting and maintaining personal goals that are not realistically achievable has been identified as a possible mechanism in the development of burnout (McCann & Pearlman, 1990).

2.7.1.3 Good caseload management

Coupled with regular time off, good caseload management has been identified as a factor that appears to mitigate work-related distress. Improved caseload management has been found to be helpful in reducing levels of Secondary Traumatic Stress; Rudolph, Stamm and Stamm, (1997), and one study found that caseload was the most significant work-related factor influencing the levels of vicarious trauma among trauma workers (Staines, 2000). Regular, deliberate breaks from the responsibility of caring for others can be an important means of preventing compassion fatigue (Figley, 2002; Rudolph, Stamm & Stamm, 1997).

2.7.1.4 Adequate referral mechanisms

A further work-related factor that appears to mediate levels of care workers work-related distress is the availability of sufficient referral mechanisms. Richter et al. (1999) found that for lay HIV counsellors, inadequate referral networks constituted a major source of work-related distress. Networking between different organisations has been identified as a mechanism that can lead to enhanced referral possibilities, and also create a more supportive environment for the people who work within them (Mathambo & Richter, 2007).

2.7.1.5 Compassion satisfaction

The fulfilment and satisfaction that caregivers can experience in relation to their work seems also to serve a mediating role. Levels of compassion satisfaction appear to have an inverse relationship with levels of secondary traumatic stress, suggesting that it may serve a protective function for care workers exposed to potentially distressing situations (Staines, 2000). This is congruent with Figley's (2002) assertion that sense of achievement – that is, satisfaction with one's efforts to help – lowers or prevents compassion stress. Insufficient intrinsic reward has been identified as a contributor to

burnout (Maslach & Leiter, 1997). On an interpersonal level, positive responses from clients and the wider community can be an important source of reward (Richter et al., 1999).

2.7.2 Organisational factors

2.7.2.1 Support

Research suggests that access to staff support and counselling is an important factor in mitigating distress (Houghton & Christensen, 2006; Miller, 2000; Stamm et al., 2002). In volunteer work, support helps reduce attrition, improves quality of care, and benefits volunteers' psychological health (Miller, 2000). Greater support of volunteers increases their perceptions of being effective in their work (Maslanka, 1996, cited in Miller, 2000), which in turn leads to a greater sense of reward from volunteering (Miller, 2000).

An important aspect of support is the provision of quality supervision, and access to consultation when necessary. Supervision has been identified as very important enabling factor for caregivers (Rudolph, Stamm & Stamm, 1997; Uys, 2002). One of the key functions of supervision in this context appears to be assisting caregivers to establish and maintain clear and appropriate boundaries (Miller, 2000). Consultation, either in person or via internet or e-mail, has also been identified as valuable in protecting care workers from compassion fatigue and burnout (Rudolph, Stamm & Stamm, 1997; Stamm et al., 2002).

Similarly, peer consultation and support from colleagues can also serve a protective function against compassion fatigue and burnout (Stamm et al., 2002). A shared organisational ethos has been demonstrated to be important in the support and retention of volunteers (Miller, 2000). It is suggested that this is in part because of the greater sense of bondedness and collaboration among workers who share a common purpose (Miller, 2000). Incidentally, it is also contended that good working relationships between caregivers enhances the quality of care provided to clients (Uys, 2002).

The provision of counselling and /or therapy for staff is another important component of support on an organisational level. It has been recommended that staff support programmes should include both individual and group counselling (Houghton & Christensen, 2006). Caregivers often experience intense emotional involvement with clients and families in the course of their work (UNAIDS, 2008), and emotional overload has been identified as a factor which increases vulnerability to burnout in this field (Miller, 2000).

2.7.2.2 Provision of training

Caregivers' training appears to play an important role in determining how they deal with the stress of their work (Miller, 2000; Stamm et al., 2002). Adequate training can prevent the frustration experienced by some volunteer caregivers as a result of lacking the skills they need for their work, and can also enhance their sense of self worth and confidence (Mathambo & Richter, 2007). Additionally, skills learnt in training can enable workers to implement appropriate self-care, and to access and utilise support when needed (Miller, 2000). It has been recommended that training should include teaching caregivers to identify potentially distressing situations and to recognise early warning signs of stress and burnout (Maslanka, 1996, cited in Miller, 2000; Stamm et al., 2002). It is also important that training is ongoing (Houghton & Christensen, 2006).

2.7.2.3 Access to resources

Lack of material resources (including transport) has been identified as a source of considerable frustration to care workers (Richter et al., 1999; Stamm et al., 2002; UNAIDS, 2008). For the care workers themselves, the accessibility of resources such as health care, including mental health care, have been identified as important (Rudolph, Stamm & Stamm, 1997).

2.7.2.4 Autonomy and collaborative management

Research indicates that volunteers are less vulnerable to burnout when they are given choices regarding where they volunteer, how much time they spend volunteering, and when to withdraw from volunteer work (Miller, 2000). Burnout has also been linked to a perception of lack of control in terms of setting priorities, choosing approaches and use of resources (Maslach & Leiter, 1997). It is therefore important that

caregivers' autonomy is recognised at an organisational level, and that policy and management are flexible and consultative.

2.7.3 Individual factors

2.7.3.1 Social support

Social support has been identified as a key factor in mitigating work-related distress (Miller, 2000). One of the benefits of having a good network of supportive relationships is the opportunity to relate to others outside of the “helper” identity, which in turn influences how individuals see themselves (Figley, 2002). Some studies indicate a higher level of burnout among single people in helping occupations than among their married counterparts (Moodley, 2001). It is however important to recognise that personal relationships are not always supportive in nature, and Figley (2002) recommends that those that pose additional demands on emotional resources should be addressed as a part of combating compassion fatigue.

2.7.3.2 Experience

Various studies have focussed on experience as a possible mediator of the stresses of working with traumatised people (Deighton et al., 2007; Miller, 2000). However, the findings from these studies seem to be conflicting, with some claiming that experience is protective against burnout and vicarious traumatisation, others finding that no significant effect exists for either vicarious traumatisation or STS, and still others asserting that it is in fact damaging in terms of emotional exhaustion (Deighton et al., 2007; Miller, 2000). Some research suggests that more experienced workers tend to have lower Burnout and Compassion Fatigue scores on the ProQOL, which could be interpreted as indicating that experience serves a protective function (Stamm, 2009). However Stamm (2009) suggests a different explanation, namely that workers with lower levels of resilience who are exposed to high levels of stress and trauma tend to leave the field, meaning that those who remain (and gain experience) are those who had higher levels of personal resilience initially.

2.7.3.3 Age

The above pattern of ‘self-selection’ of resilient care workers may also explain why many studies suggest that age is negatively correlated with burnout among people

involved in caring work – that is, young workers appear to be at greater risk than their older colleagues (Miller, 2000; Moodley, 2001). However, other studies have however found no significant association between burnout and age (Miller, 2000).

2.7.3.4 Education level

Another factor for which there have been conflicting findings is education. Some studies suggest that there is a positive correlation between education level and levels of burnout and vicarious trauma (Moodley, 2001, Staines, 2000). However, Rudolph et al. (1997) reported that among healthcare workers, participants with Masters level education had a higher risk of burnout and compassion fatigue than those with bachelors degrees, while those with Doctorates were at moderate risk – lower than those with Masters, but higher than those with bachelors.

2.7.3.5 Ability to disengage

Disengagement refers to a conscious distancing of oneself from the client's distress and issues between contacts (Figley, 2002). Figley (2002) found that disengagement lowered the risk of work-related distress among psychotherapists. In the context of the present study, it seems likely that caregivers who are part of the same community as their clients would find it particularly challenging to disengage, especially in cases where they are facing many of the same problems within their own families.

2.7.3.6 Coping strategies

The specific coping strategies that individual care workers employ to deal with their work-related stress also appear to play an important part in determining its impact on a personal level. Higher levels of Compassion Satisfaction have been reported among individuals who use so-called approach coping responses, such as logical analysis, positive reappraisal, problem solving, and seeking guidance and support, than among their counterparts who tend more towards avoidance (Staines, 2000).

2.7.3.7 Sense of personal efficacy

A sense of efficacy was found to be a key reward of volunteer work that reduced burnout and the desire to withdraw from the work (Maslanka, 1996, cited in Miller, 2000; Richter et al., 1999).

2.8 Summary

This chapter reviews literature relevant to the focus of this research. This includes theories of compassion satisfaction, burnout and compassion fatigue; and elaborations of their aetiologies, presentation, and sequelae. Issues surrounding HIV and AIDS in the geographical and social contexts of the study are examined, with particular emphasis on the challenges of caring for those infected. The profiles and roles of caregivers are explored; as are the specific challenges they encounter in their work, which potentially increase their vulnerability to burnout and compassion fatigue. The chapter concludes with an overview of factors which research suggests might ameliorate the effects of these challenges.

CHAPTER 3 - METHODOLOGY

3.1 Introduction

This study represents an attempt to explore how caregivers are affected by their work with people affected and infected with HIV and AIDS. This chapter reiterates the aims, objectives and research questions as stated in the first chapter, details the instruments used, and describes the method followed in the collection and analysis of data.

3.2 Aims and objectives

- 3.2.1** To assess the extent of compassion fatigue and burnout among local HIV and AIDS caregivers;
- 3.2.2** To explore which personal variables mitigate the risk of these problems;
- 3.2.3** To explore which variables are associated with compassion satisfaction among caregivers.

3.3 Research questions

- i) To what extent are caregivers in the field of HIV and AIDS at risk for compassion fatigue and burnout, and what are their levels of compassion satisfaction?
- ii) Among these caregivers, what relationships exist between personal attributes, such as age, marital status, training and experience; and levels of compassion fatigue, burnout and compassion satisfaction?
- iii) Which of the above personal attributes are most associated with compassion fatigue, burnout and compassion satisfaction among caregivers?

3.4 Research design

This was an exploratory quantitative study which employed a non-experimental design.

3.5 Sampling

Purposive and snowball sampling approaches were used to recruit participants, who were all caregivers working in the field of HIV and AIDS. Geographically, sampling took place in Kwa-Zulu Natal, targeting participants working in uMngeni Municipality/ Midlands area. This was done by approaching NGO's and community organisations that provide services in this area. Although generalisability of the research findings is limited by the use of non-random selection, it was anticipated that methods such as snowball sampling would be needed to access and recruit sufficient participants. The study aimed to recruit a total of approximately 75 participants; however, an excellent response by the relevant community meant that a total of 102 participants completed questionnaires. Of these, 19 were excluded from the dataset, leaving a total sample of 83 participants.

Questionnaires were excluded from the dataset in the following cases: if questionnaires were not completed; if more than 10% (i.e. three) responses had been omitted on the ProQOL; if responses were unscorable because of inappropriate responses to Likert-type items (e.g. responses of numbers other than 1-5), or multiple responses were given to individual items; responses from participants who were newly trained volunteers and had not yet begun working in the community; and respondents who indicated that they were no longer involved in direct care (e.g. training facilitators).

3.6. Instruments

Two self-report questionnaires were used in this study: (1) a questionnaire pertaining to personal attributes that previous research indicated may be relevant to the phenomena of interest, and (2) the Professional Quality of Life Scale – Version 5 (ProQOL) (Stamm, 2009).

3.6.1. The personal attributes questionnaire

This questionnaire was designed to investigate selected personal attributes found in literature to influence positive and negative sequelae of caring work. A database of factors listed in existing research was created (see Appendix 2), and from this a list of areas to be covered in the questionnaire was selected. The resulting questionnaire was

also translated into Zulu, as it was anticipated that this would be the first language of many participants. The Zulu form of the questionnaire was checked by a second translator to ensure accuracy. Both translators were first language Zulu speakers from the same region of KwaZulu-Natal as the research participants, in order to avoid potential problems with regional language differences. A copy of the final questionnaire in both forms can be found in Appendix 4.

3.6.1.1 Description

Specific areas of enquiry covered in this questionnaire were as follows:

(i) Demographics section

- (a) Gender
- (b) Age
- (c) Current marital status – whether married, in a long-term relationship, divorced, separated, widowed, single/ never married
- (d) Scholastic education – highest grade reached in school
- (e) Post school qualifications – any certificate courses, diplomas or degrees obtained after leaving school
- (f) Occupational status – whether currently employed, studying, retired, voluntary workers or unemployed
- (g) Personal history of HIV and AIDS – whether caregivers or somebody close to them has been directly affected by HIV or AIDS

(ii) Attributes related to work as a caregiver

- (a) Experience – how long the respondent has worked as a caregiver
- (b) Remuneration status – whether voluntary/unpaid, given stipend, or employed as caregiver
- (c) Caseload – estimated number of clients seen per week
- (d) Level of training – the length of training the caregiver has received
- (e) Perceived adequacy of training – whether caregivers feel that their training prepared them adequately for the work they are doing
- (f) Ongoing training and development – whether caregivers have access to such
- (g) Access to therapist or counsellor if required by caregiver

- (h) Personal identification with clients – the degree to which caregivers feel that they are similar to their clients
- (i) Role clarity – the degree to which they are certain of the extent and limits of their role
- (j) Sense of personal efficacy – whether respondents perceive themselves to be performing their caregiving work well
- (k) Sufficiency of referral networks – extent to which caregivers are confident in their ability to refer clients to appropriate sources of assistance in cases where they have needs that fall outside the limits of the caregiver's role
- (l) Secondary stigma – degree to which caregivers perceive that their work exposes them to secondary stigmatisation.
- (m) Social support – whether caregivers perceive those close to them as a source of support and strength
- (n) Supervision and mentoring – whether they receive help and advice regarding clients from people within their organisation
- (o) Self-care – extent to which caregivers consciously engage in activities that are pleasurable and relaxing.

3.6.2 Professional Quality of Life Scale – Version 5 (ProQOL)

3.6.2.1 Description

The ProQOL 5 consists of 30 items measured in a 5-point Likert scale self-report questionnaire. Results are scored on three subscales, namely Secondary Traumatic Stress, Burnout and Compassion Satisfaction (see Table 3.1 below). This measure is the current version of the Compassion Fatigue Self Test developed by Figley in the 1980s (Stamm, 2009). It is the most widely used measure used to assess the positive and negative effects of working with people who have experienced trauma (Stamm, 2009). The ProQOL was developed in English, but has previously been translated into eight additional languages (Stamm, 2009).

For this research, the ProQOL was also made available in Zulu, as it was anticipated that this would be the first language of many of the participants. To ensure an accurate and accessible Zulu version while also maintaining the integrity of the measure, a procedure of translation and back-translation by independent translators was followed. Where it proved inappropriate or impossible to translate particular items on the

measure directly, the translation was done in consultation with the researcher so as to reflect the intended meaning of the items as accurately as possible.

Table 3.1 Definition of Subscales of Professional Quality of Life Scale

ProQOL 5 Subscale	Items	Definition
Compassion Satisfaction (CS)	10	Positive sequelae of helping others; i.e. pleasure derived from doing work well (Stamm, 2009).
Burnout (BO)	10	Negative sequelae of helping others, specifically associated with a sense of futility and helplessness (Stamm, 2009).
Secondary Traumatic Stress (STS)	10	Negative sequelae of helping others, specifically associated with fear and work-related trauma (Stamm, 2009).

3.6.2.2 Validity and reliability:

Construct validity is reported as good, with over 200 published research papers and more than 100 000 internet articles to date (Stamm, 2009). The ProQOL or earlier versions thereof have been used in many of these publications (Stamm, 2009). Although it is reported that there is shared variance between the Burnout (BO) and Secondary Traumatic Stress (STS) subscales, the measure's author contends that this can be explained as a reflection of the distress that is common to both these conditions. The two subscales measure separate constructs and are distinct in that the STS scale addresses fear while the BO scale does not (Stamm, 2009).

The concise ProQOL manual reports alpha reliabilities and standard errors as detailed in Table 3.2 below.

Table 3.2 ProQOL Subscale Alpha Reliabilities and Standard Errors (Stamm, 2009)

Subscale	Alpha reliability	Standard error
Compassion Satisfaction	$\alpha = .88$ (n = 1130)	.22
Burnout	$\alpha = .75$ (n = 976)	.21
Secondary Traumatic Stress	$\alpha = .81$ (n = 1135)	.20

The measure's item-to-scale properties are reported to be good, as no single item either adds to or subtracts from the overall quality of the scale (Stamm, 2009).

3.6.2.3 Normed population

Although ProQOL normative data does not exist for the specific population of interest in this study, the norms contained in the manual reflect a large database created from multiple studies in international settings. No scale score differences were observed between different countries (Stamm, 2009). According to Stamm (2009), the ProQOL is appropriate for use in any population where there is a possibility of being exposed to another person's potentially traumatic material as a part of either paid or volunteer work.

3.6.2.4 Scoring and interpretation

First, scoring for 5 items on the Burnout (BO) subscale is reversed (see appendix). Then the ratings for items on each subscale are summed and converted to T-scores. The mean score for all subscales is therefore 50 with a standard deviation of 10. The test manual advises that scores are best regarded in their continuous forms, as the use of cut-point scoring tends to lead to the commission of type I errors; however cut scores are provided in the manual for screening purposes. A summary of subscale score interpretation is provided in Table 3.3 below.

Table 3.3 Interpretation of ProQOL Scores

Subscale	Interpretation of scores
Compassion Satisfaction (CS)	High scores reflect high levels of satisfaction with helping work, characterised by enjoyment and feeling invigorated, effective and successful.
Burnout (BO)	High scores reflect high risk of burnout, characterised by feelings of futility, ineffectiveness, exhaustion and being overwhelmed.
Secondary Traumatic Stress (STS)	High scores reflect high risk of secondary traumatic stress, characterised by feeling fearful, experiencing symptoms of trauma, and being preoccupied with thoughts of people one has helped.

(Stamm, 2009)

3.7. Procedure

The researcher approached various community-based and non-governmental organisations working in the KwaZulu-Natal Midlands area. Positive responses were

received from 6 organisations. The researcher arranged to do data collection at the usual meeting venues of the respective groups in Mpophomeni, Lidgetton and Howick. Attendance at data collection sessions ranged from one to 25 participants.

Potential participants were given participant information sheets, and the researcher explained the contents orally. Information sheets, consent forms and questionnaires were supplied in either English or Zulu – or in some cases, both languages – according to each participant's preference. Participants then signed the informed consent sheets, and inserted these into a sealed collection box. Questionnaires were distributed, and a brief explanation of these was given by the researcher. When participants had completed their questionnaires, they inserted these into a second collection box which was emptied by the researcher between data collection sessions.

3.8 Ethical considerations

The overall aims and objectives of the study were explained to participants both verbally and in writing, as part of the informed consent they were asked to sign on enrolment (see Appendix 3). Participants were informed that their participation in this research was on a voluntary basis, and that they could choose to withdraw at any time without adverse consequences. Although no monetary incentives were offered to participants, the researcher supplied refreshments as a gesture of appreciation. Participants were also informed that they will be able to access feedback on the key findings through a report which will be presented to their respective organisations.

Questionnaires and informed consent were provided in both English and Zulu so that participants could choose the language with which they felt most comfortable. The ProQOL questionnaire was explained using practice items to familiarise participants with the procedure, and verbal clarification and explanation of questionnaire items was provided in either language when required. A Zulu-speaking research assistant assisted with translation and clarification where needed.

Confidentiality was maintained by assigning participant codes, and informed consent documents will be kept in secure storage separately from completed questionnaires. Questionnaires were anonymous and there was no link between informed consent

sheets and questionnaires. As required by law, data will be retained for a period of five years, after which it will be destroyed.

3.9 Data analysis

Data was analysed using SPSS version 15.0 (SPSS, Inc., Chicago IL). The procedures used are outlined below.

3.9.1 ProQOL scores (dependent variables)

Where participants had omitted responses for three or fewer items (i.e. less than 10% of total items), these items were coded as “missing”, as suggested by Stamm (2005).

Raw scores for each subscale (i.e. Compassion Satisfaction, Burnout, and Secondary Traumatic Stress) were converted to T-scores as specified in the scale manual. These subscale scores were treated as the dependent variables. Descriptive statistics for the dataset were then generated, and the scores of respondents were compared to those of the reference norm group. An analysis of intra-test reliability was also performed.

3.9.2 Personal attributes (independent variables)

Frequencies and descriptive statistics were generated for personal attributes, which constituted the independent variables in this study. The majority of this data was measured at categorical and ordinal levels. Tests of significance (one-way ANOVAs and independent samples t-tests) were then utilised to compare mean levels of the dependent variables at each level of the independent variables. Effect size was calculated where applicable.

3.9.3 Correlation

Pearson’s correlation was used to examine the relationships between variables that were suitable for this type of analysis (i.e. continuous data). These included the subscale scores of the ProQOL and some demographic data such as age and caseload of caregivers.

3.10 Summary

This chapter reiterates the aims and objectives of this study, and outlines the methodology used in the collection and analysis of data. Details of the sampling, the instruments used, and the procedure followed in data collection are given. Ethical considerations are addressed, and the methods used to analyse the data are described.

CHAPTER 4 – RESULTS

4.1 Introduction

This chapter presents the results of the statistical analyses described in the previous chapter. In the case of significance tests, group descriptive statistics are included here only in cases where there is a significant effect (a summary of descriptive statistics for all groups may be found in Appendix 4).

4.2 The Professional Quality of Life Scale (ProQOL)

The constructs measured by the three subscales of the ProQOL – namely Compassion Satisfaction, Burnout and Secondary Traumatic Stress – constituted the dependent variables for this study. The descriptive statistics are detailed in Table 4.1 below.

Table 4.1 Descriptive Statistics of Dependent Variables

Variable	N	Mean	Median	Mode	Standard deviation
Compassion Satisfaction	82	56.9	58.6	69	9.37
Burnout	78	50.8	51	56	9.60
Secondary Traumatic Stress	79	69.9	70.6	72	8.78

4.2.1 Compassion Satisfaction subscale

As seen in Table 4.1 above, respondents' mean score for Compassion Satisfaction was 56.9 ($SD = 9.37$), corresponding with the 73rd percentile of the reference norm group (Stamm, 2009). When compared against the cut scores which are included in *The concise ProQOL manual* (Stamm, 2009) for screening purposes, the majority of respondents (53, 7%) scored above the 75th percentile on Compassion Satisfaction (see Table 4.2 below). This indicates that they derive relatively high levels of pleasure and personal reward from their work as caregivers.

Table 4.2 Respondents' Levels of Compassion Satisfaction in Relation to Subscale Cut Scores

Percentile range	Frequency (N=82)	Percent	Cumulative percent
≤25 th	10	12.2	12.2
≤50 th	10	12.2	24.4
≤75 th	18	21.9	46.3
>75 th	44	53.7	100

4.2.3 Burnout subscale

The mean score for Burnout was 50.8 ($SD = 9.60$), corresponding with the 50th percentile of the reference group. The majority of respondents (55.1%) scored above the reference norm group's mean for this subscale, with 28, 2% scoring above the 75th percentile (see Table 4.3 below). This indicates that despite the group mean score for this subscale being close to the reference mean, a substantial proportion of the respondents have a relatively high risk for burnout.

Table 4.3 Respondents' Levels of Burnout in Relation to Subscale Cut Scores

Percentile range	Frequency (N=78)	Percent	Cumulative percent
≤25 th	17	21.8	21.8
≤50 th	18	23.1	44.9
≤75 th	21	26.9	71.8
>75 th	22	28.2	100

4.2.4 Secondary Traumatic Stress subscale

The mean score for Secondary Traumatic Stress was 69.9 ($SD = 8.78$), which corresponds with the 95th percentile of the reference group. The overwhelming majority (93, 7%) of respondents scored above the cut score for the 75th percentile, as evidenced in Table 4.4 below. This indicates that most participants in this study have a relatively high risk of Secondary Traumatic Stress as a result of their work as caregivers.

Table 4.4 Respondents' Levels of Secondary Traumatic Stress in Relation to Subscale Cut Scores

Percentile range	Frequency (N=79)	Percent	Cumulative percent
≤25 th	0	0	0
≤50 th	0	0	0
≤75 th	5	6.3	6.3
>75 th	74	93.7	100

4.2.5 Correlations

There were highly significant negative correlations between Compassion Satisfaction and Burnout, $r(75) = -.536$, $p < .0005$ (see Figure 4.1), and between Compassion Satisfaction and Secondary Traumatic Stress, $r(76) = -.410$, $p < .0005$ (Figure 4.2). The correlation between Burnout and Secondary Traumatic Stress was highly significant, $r(72) = .456$, $p < .0005$ (Figure 4.3). The complete correlation matrix can be found in Appendix 5.

Figure 4.1 Correlation between Burnout and Compassion Satisfaction

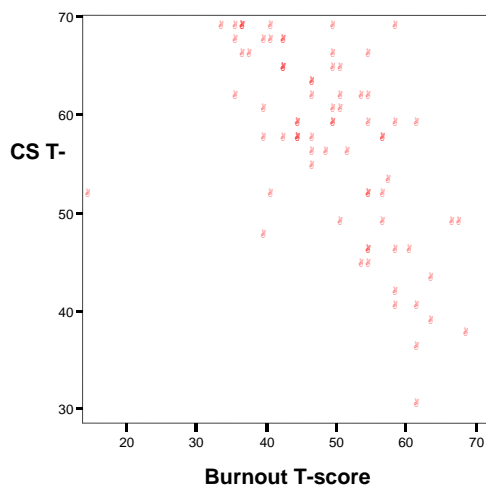


Figure 4.2 Correlation between Compassion Satisfaction and Secondary Traumatic Stress

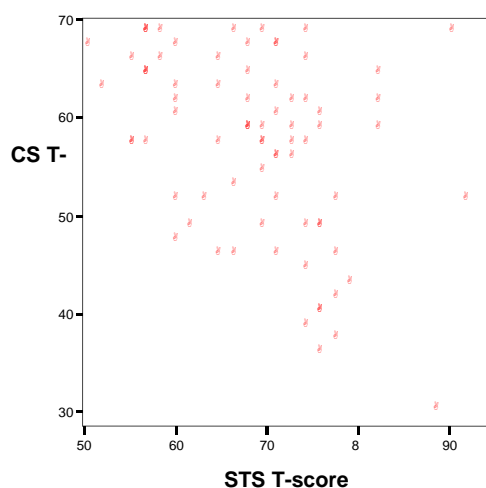
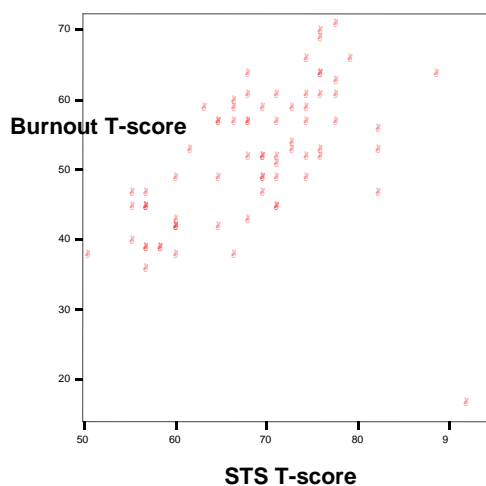


Figure 4.3 Correlation between Burnout and Secondary Traumatic Stress



4.2.6 Intratest reliability

Reliability analysis of the subscales indicated satisfactory intratest reliability. The results are summarized in Table 4.5 below.

Table 4.5 Professional Quality of Life Scale Intratest Reliability Statistics

Subscale	N	N of items	Cronbach's alpha	Alpha quoted in scale manual
Compassion Satisfaction	82	10	0.882	0.88
Burnout	78	10	0.763	0.75
Secondary Traumatic Stress	79	10	0.715	0.81

4.3 Personal attributes

A frequency distribution of participants' responses concerning independent variables scored on an ordinal scale is summarised in Table 4.6 below. In the case of continuous variables, the descriptive statistics are contained in Table 4.7 below.

Table 4.6 Frequency Distribution of Independent Variables (Ordinal Data)

Variable	Levels	n	%
Gender	Male	11	13.6
	Female	70	86.4
Current marital status	Single	53	66.3
	In a relationship	27	33.8
Highest level of post-school education	None	6	8.6
	Certificate(s)	54	77.1
	Diploma	9	12.9
	Degree	1	1.4
Occupational status	Unemployed	5	6.1
	Employed	31	37.8
	Volunteer	41	50
	Studying	4	4.9
	Retired	1	1.2
Personal history of HIV or AIDS	No	34	43
	Yes	45	57
Remuneration status	No remuneration	12	15
	Stipend	32	40
	Paid	36	45
Perceived adequacy of training	Inadequate	5	6.1
	Partly adequate	40	48.8
	Adequate	37	45.1

Variable	Levels	n	%
Access to ongoing training	No	13	15.7
	Yes	70	84.3
Access to counselling	No	37	45.1
	Yes	45	54.9
Identification with clients	No	7	8.5
	In part	46	56.1
	Yes	29	35.4
Role clarity	Frequently unsure	13	15.7
	Some uncertainty	28	33.7
	Certain of role	42	50.6
Perceived efficacy	No	4	4.8
	Unsure	12	14.5
	Yes	67	80.7
Referral mechanisms	Insufficient	1	1.2
	Partly sufficient	9	10.8
	Sufficient	73	88.0
Perceived stigma	None	29	36.3
	Sometimes	32	40
	A lot	19	23.8
Social support	No	3	3.7
	Sometimes	21	25.9
	Yes	57	70.4
Organisational support	No	6	7.4
	Yes	75	92.6
Engagement in self-care	Seldom/ never	4	4.9
	Sometimes	34	42
	Regularly	43	53.1

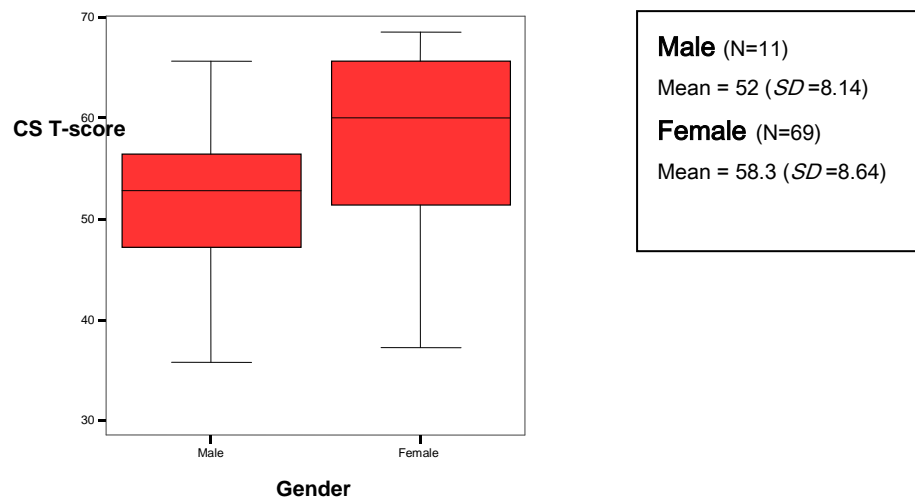
Table 4.7 Descriptive Statistics of Independent Variables (Continuous Data)

Variable	Mean	Median	Mode	SD	Range
Age	33.2	34	36	9.57	55
Highest grade in school	11	11	12	1.34	8
Experience (months)	47.9	36	24	41.6	179
Caseload (estimated number of clients/ week)	19.2	20	20	14	59
Caregiver training (weeks)	19.6	3	3	38.8	208

4.3.1 Gender

Two respondents omitted to indicate their gender on the questionnaire. Of the remaining 81 participants, 11 were male and 70 were female (see Table 4.6). Female participants had significantly higher levels of Compassion Satisfaction than their male counterparts, $t(78) = -2.3, p = .024, d = .745$. (see Figure 4.4 below).

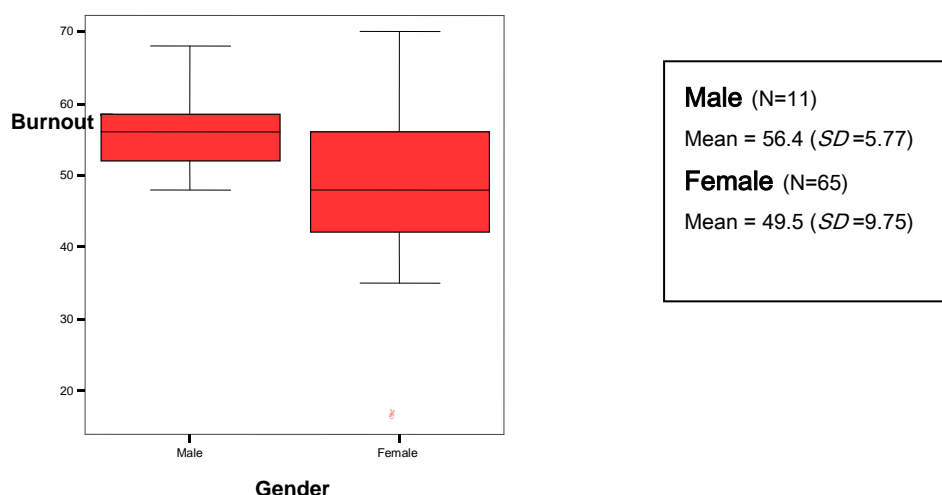
Figure 4.4 Compassion Satisfaction by Gender



Mean levels of Burnout were significantly higher among male caregivers than among female caregivers, $t(74) = 2.26, p = .027, d = 0.738$ (Figure 4.5 below).

However there was no significant difference in the mean Secondary Traumatic Stress scores of men and women, $t(21.4) = 1.41, p = .172$.

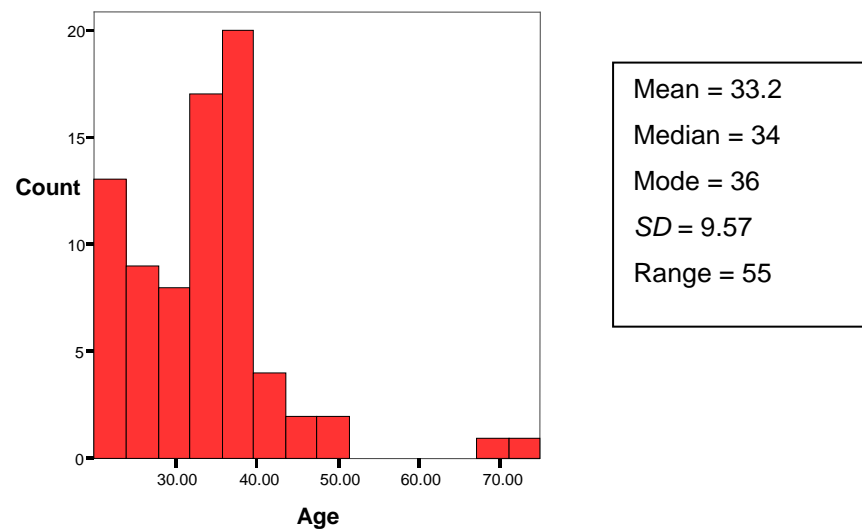
Figure 4.5 Burnout by Gender



4.3.2 Age

Six participants omitted to indicate their age. The distribution and descriptive statistics concerning the remaining 77 are summarised in Figure 4.6 below.

Figure 4.6 Frequency Distribution - Age



Correlations between age and the dependent variables were not significant: Compassion Satisfaction $r(74) = .154$, $p = .184$; Burnout $r(71) = 0.017$, $p = .889$; and Secondary Traumatic Stress $r(71) = .070$, $p = .559$.

4.3.3 Current marital status

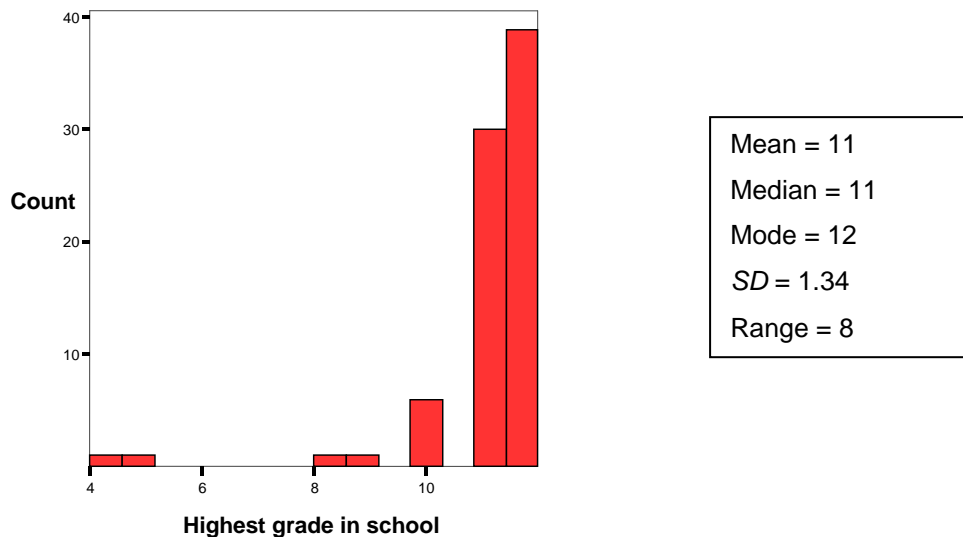
Three participants did not indicate their marital status on the questionnaire. For the purposes of this analysis, the six categories on the questionnaire were collapsed into two, namely (1) single or (2) in a relationship. The frequency distribution of the 80 respondents can be found in Table 4.6 above.

There were no significant differences in levels of the dependent variables according to current marital status: for Compassion Satisfaction $t(46.1) = 1.965$, $p = .55$; for Burnout $t(74) = -0.555$, $p = .581$; and for Secondary Traumatic Stress $t(74) = -1.97$, $p = .531$.

4.3.4 Scholastic education

Four participants did not indicate their highest level of schooling, leaving a total of 79 respondents to this question. As can be seen in Figure 4.7 below, the majority of respondents indicated that they had reached grade 11 or higher.

Figure 4.7 Frequency distribution – Highest Grade in School

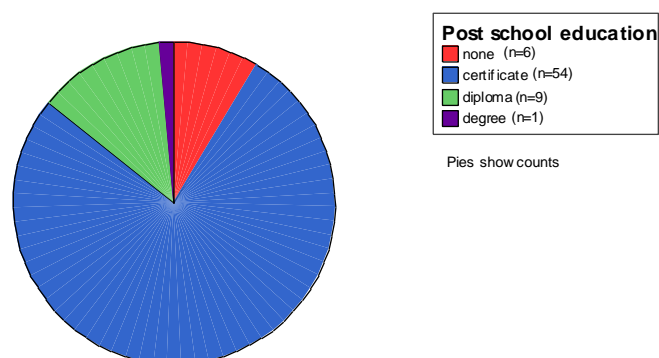


Correlations between scholastic education level and the dependent variables were not significant: Compassion Satisfaction $r(76) = -.177, p = .309$; Burnout $r(73) = -.133, p = .256$; and Secondary Traumatic Stress $r(73) = -.225, p = .52$.

4.3.5 Post-school education

Thirteen respondents did not report their highest level of education after leaving school, leaving a total of 70. The majority (77%) indicated that they had attended certificate courses – see Figure 4.8 below.

Figure 4.8 Frequency Distribution – Post-School Education

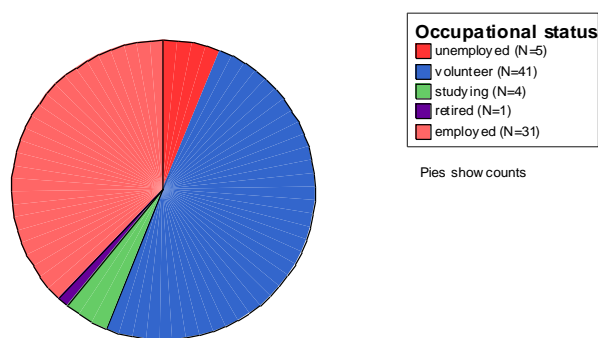


The mean levels of the dependent variables did not differ significantly between caregivers with different levels of post-school education: for Compassion Satisfaction $F(3,68) = 0.622, p = .603$; Burnout $F(3,66) = 0.548, p = .652$; and Secondary Traumatic Stress $F(3,65) = 0.733, p = .537$.

4.3.6 Occupational Status

Only one respondent failed to indicate an occupational status. Of the remaining 82, only 31 were in formal employment (see Figure 4.9 below).

Figure 4.9 Frequency Distribution – Occupational Status

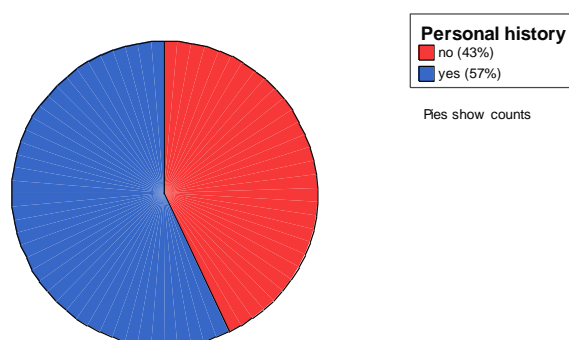


No significant differences were found in levels of the dependent variables between the five groups: for Compassion Satisfaction $F(4,80) = 2.08, p = .092$; Burnout $F(4,76) = 1.515, p = .207$; and Secondary Traumatic Stress $F(4,77) = 0.926, p = .454$.

4.3.7 Personal History

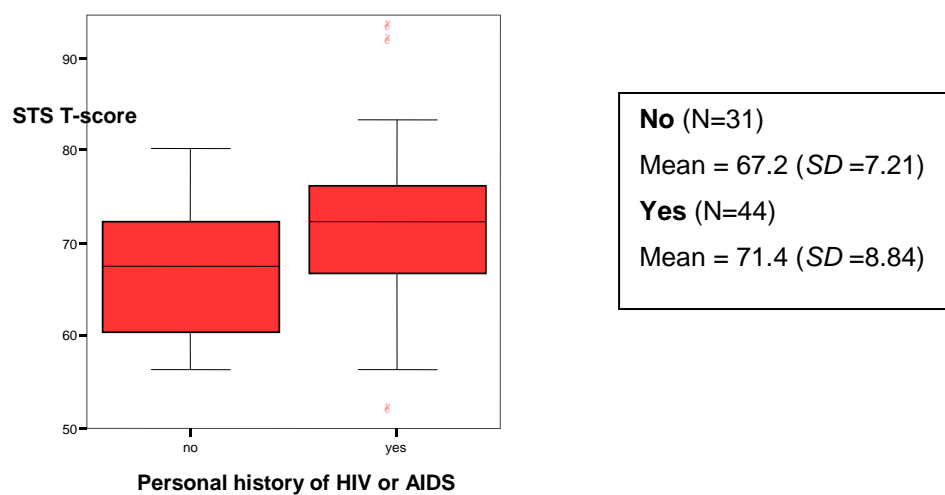
Four participants did not indicate whether they or somebody close to them had been directly affected by HIV or AIDS. The distribution of the remaining 79 is summarized in Figure 4.10 below.

Figure 4.10 Frequency Distribution – Personal History of HIV or AIDS



There was no significant difference in levels of Compassion Satisfaction or Burnout between caregivers with personal histories concerning HIV or AIDS and those without – $t(57.5) = -1.03$, $p = .309$ and $t(73) = 0.316$, $p = .376$ (one-tailed) respectively. However there was a significant difference in mean levels of Secondary Traumatic Stress between the two groups, $t(73) = -2.18$, $p = .0165$ (one-tailed), $d = 0.5104$ (see Figure 4.11). Caregivers who had been directly affected themselves or through somebody close to them had significantly higher means of Secondary Traumatic Stress than those who lacked this personal history.

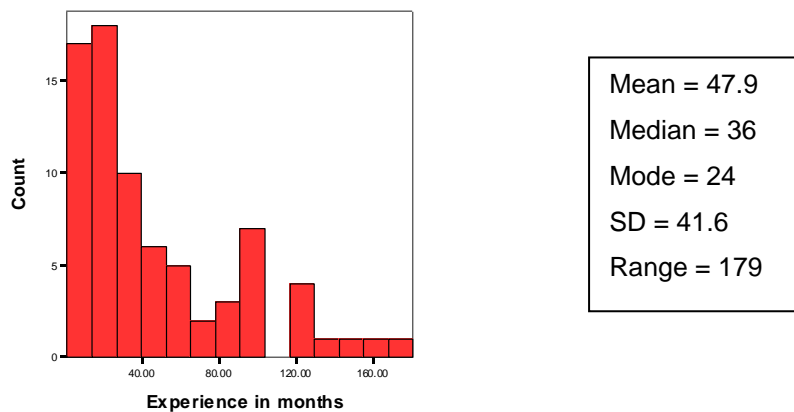
Figure 4.11 Secondary Traumatic Stress by Personal History



4.3.8 Experience

Seven respondents either did not indicate how long they had been caregivers or indicated their experience in inexact terms that could not be analysed (for example, writing that they had been caregivers for “a very long time”). The distribution and descriptive statistics of the remaining 75 are summarised in Figure 4.12 below.

Figure 4.12 Frequency Distribution - Experience

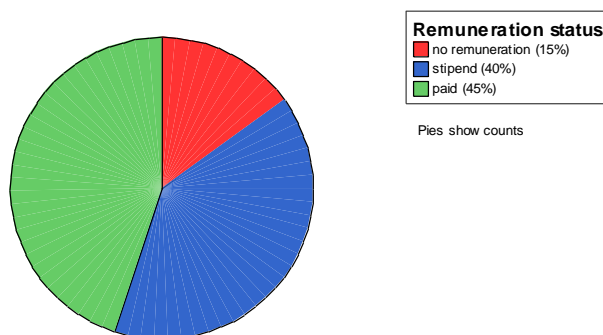


Correlations between levels of the dependent variables and caregivers' experience were not significant: experience and Compassion Satisfaction $r(73) = -.068, p = .56$; experience and Burnout $r(69) = -.069, p = .57$; and experience and Secondary Traumatic Stress $r(69) = .106, p = .377$.

4.3.9 Remuneration

Three participants did not indicate whether they performed their caregiving work in a voluntary capacity, were paid to do so, or received stipends. Of the 80 who did answer this question, more than half (55%) reported that they either received no remuneration or only stipends for their work (see distribution in Figure 4.13 below).

Figure 4.13 Frequency Distribution – Remuneration Status



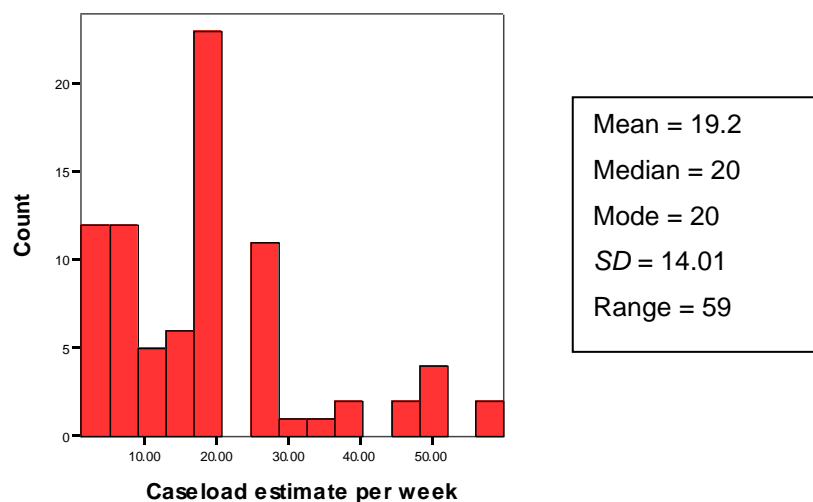
There were no significant differences in mean levels of the dependent variables across the three groups: for Compassion Satisfaction $F(2, 78) = 1.506, p = .228$; for Burnout $F(2, 74) = 0.866, p = .430$; and Secondary Traumatic Stress $F(2, 76) = 2.16, p = .122$.

4.3.10 Caseload

Two participants failed to respond to this item, leaving a total of 81 respondents. The distribution and descriptive statistics are summarised in Figure 4.14 below.

There were no significant correlations between mean levels of the dependent variables and caregivers' estimated weekly caseloads: for Compassion Satisfaction, $r(78) = .072, p = .523$; Burnout, $r(74) = -.015, p = .895$; and Secondary Traumatic Stress, $r(75) = .056, p = .63$.

Figure 4.14 Frequency Distribution – Caseload

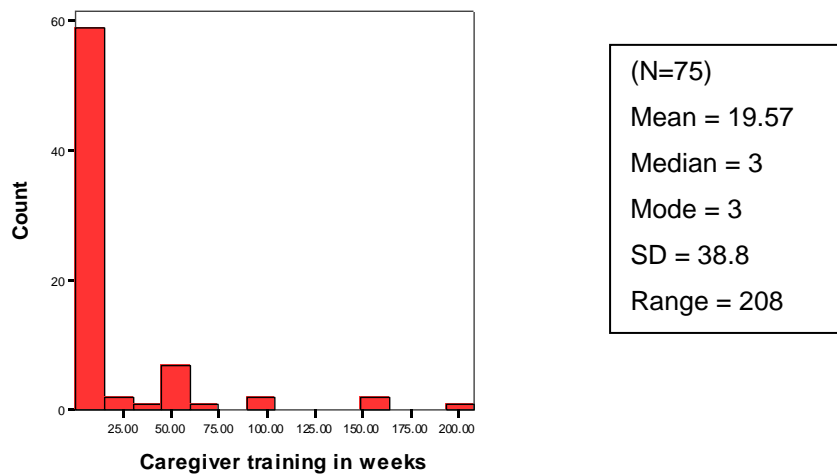


4.3.11 Length of training

Eight participants either did not indicate the length of their training to be caregivers or gave answers that were not suitable for quantitative analysis. The total number of respondents for this item was therefore 75 (see Figure 4.15 below for summary of the distribution and descriptive statistics).

None of the correlations between mean levels of the dependent variables and length of caregivers' training were significant: training and Compassion Satisfaction, $r(72) = -.136, p = .248$; training and Burnout, $r(69) = .225, p = .06$; and training and Secondary Traumatic Stress, $r(69) = .106, p = .377$.

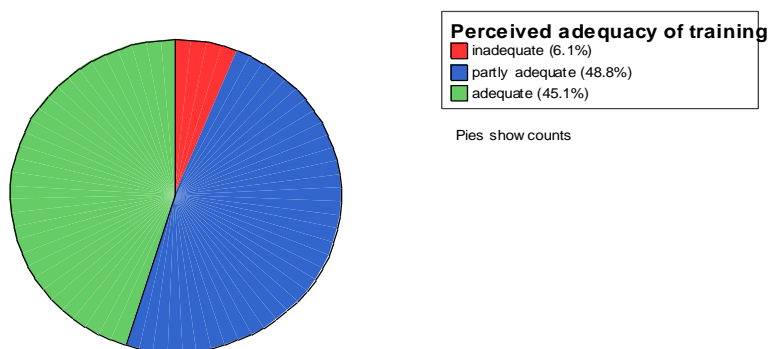
Figure 4.15 Frequency Distribution – Length of Training



4.3.12 Perceived adequacy of training

Only one participant failed to respond to this item. Most of the 82 respondents (54.9%) indicated that they felt their training had not completely prepared them for the work they do as caregivers (see Figure 4.16 below).

Figure 4.16 Frequency Distribution – Perceived Adequacy of Training

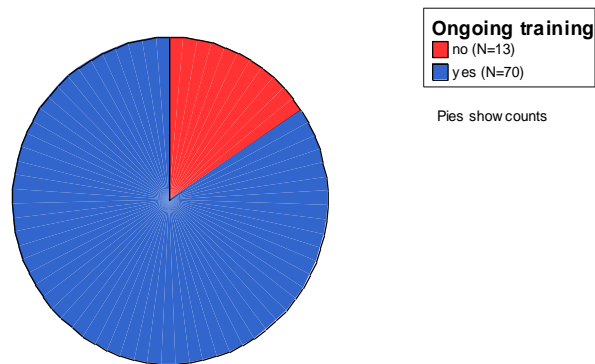


No significant differences were found in mean levels of the dependent variables between caregivers who perceived their training as inadequate, partly adequate or sufficient: for Compassion Satisfaction, $F(2, 80) = 0.233, p = .792$; Burnout, $F(2, 76) = 0.197, p = .822$; and Secondary Traumatic Stress, $F(2, 77) = 2.486, p = .090$.

4.3.13 Access to ongoing training

This item was responded to by all 83 participants, the majority of whom (83.4%) indicated that they did have opportunities to supplement their training on an ongoing basis (see distribution in Figure 4.17).

Figure 4.17 Frequency Distribution – Access to Ongoing Training



There were no significant differences in mean levels of the dependent variables between caregivers with access to ongoing training and those without: for Compassion Satisfaction, $t(80) = -0.555$, $p = .580$; Burnout, $t(76) = 1.557$, $p = .124$; and Secondary Traumatic Stress, $t(77) = 1.938$, $p = .56$.

4.3.14 Access to counselling and therapy

All but one participant indicated whether they have access to a counsellor or therapist if they are feeling distressed. Slightly over half of the 82 respondents (54.2%) affirmed that they are able to access this assistance if they require it (refer to Table 4.6 for frequency distribution).

The differences in mean scores for the dependent variable between the two groups were not significant in the cases of Compassion Satisfaction, $t(79) = -0.718$, $p = .90$ or Burnout, $t(75) = 1.38$, $p = .171$. However there was a significant difference in the mean levels of Secondary Traumatic Stress between those caregivers who had access to counselling or therapy and those who did not, $t(76) = 3.558$, $p = .001$, $d = 0.517$ (see Figure 4.18 below). Caregivers who were not able to access this help when needed had significantly higher levels of Secondary Traumatic Stress than their counterparts who could.

Figure 4.18 Secondary Traumatic Stress by Access to Counselling/ Therapy

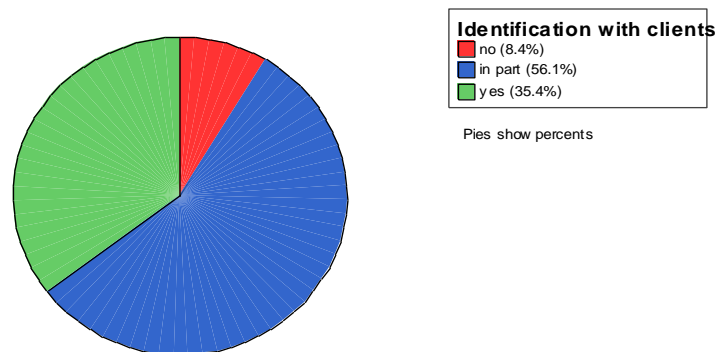


4.3.15 Identification with clients

One participant did not indicate a response to this item. Most caregivers indicated that they did view their clients as similar to themselves at least in part (see Figure 4.19).

There were no significant differences in the mean levels of dependent variables between the three groups of caregivers: for Compassion Satisfaction, $F(2) = 0.830$, $p = .44$; Burnout, $F(2) = 1.924$, $p = .153$; and Secondary Traumatic Stress, $F(2) = 0.419$, $p = .659$.

Figure 4.19 Frequency Distribution – Identification with Clients

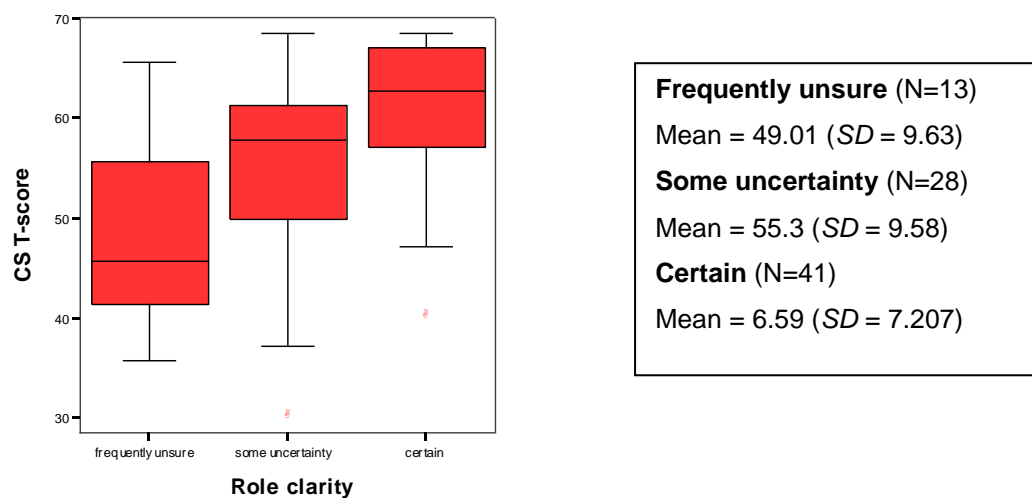


4.3.16 Role clarity

All of the 83 participants recorded a response to this item. Almost half (49.4%) evidenced some degree of uncertainty regarding the scope of their responsibilities to clients (refer to Table 4.6 for frequency distribution).

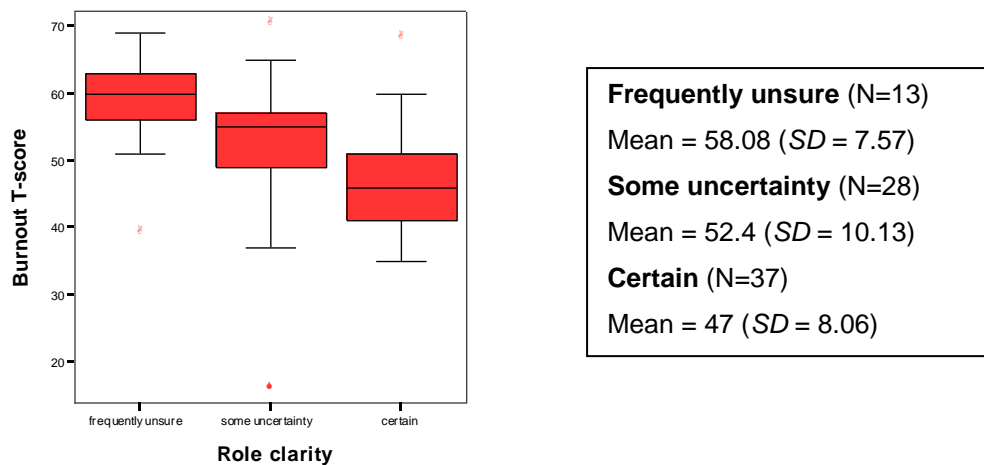
There was a significant systematic difference in mean levels of Compassion Satisfaction between the three groups, $F(2,81) = 10.062$, $p < .0005$, $\eta^2 = .203$. Caregivers who were certain of the limits of their roles had significantly higher levels of Compassion Satisfaction than caregivers who had some uncertainty and those who were frequently unsure of the limits of their roles (refer to Figure 4.20 below).

Figure 4.20 Compassion Satisfaction by Role Clarity



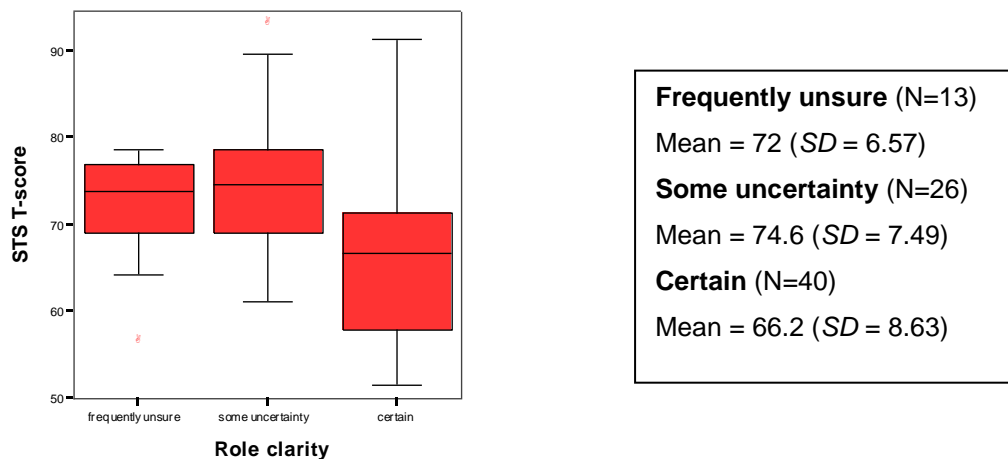
There was also a significant systematic difference in mean levels of Burnout between the three groups of caregivers, $F(2,77) = 8.42$, $p = .001$, $\eta^2 = .183$. Caregivers who were certain of the limits of their responsibilities had significantly lower levels of Burnout than those who were frequently unsure or those with some uncertainty (see Figure 4.21 below).

Figure 4.21 Burnout by Role Clarity



A further significant systematic difference was found in mean levels of Secondary Traumatic Stress between the three groups, $F(2,78) = 9.41$, $p < 0.0005$, $\eta^2 = 0.198$. The caregivers who indicated that they were certain of their roles had significantly lower levels of Secondary Traumatic Stress than their counterparts who evidenced some uncertainty and frequent uncertainty (see Figure 4.22).

Figure 4.22 Secondary Traumatic Stress by Role Clarity



4.3.17 Perceived efficacy

All participants responded to this item, with the majority (80.7%) indicating that they felt satisfied that they performed their caregiving work well. There was a significant systematic difference between group means for Compassion Satisfaction, $F(2, 81) = 3.18$, $p = .047$, $\eta^2 = .0745$. Caregivers who thought that they were doing a good job had significantly higher levels of Compassion Satisfaction than those who were

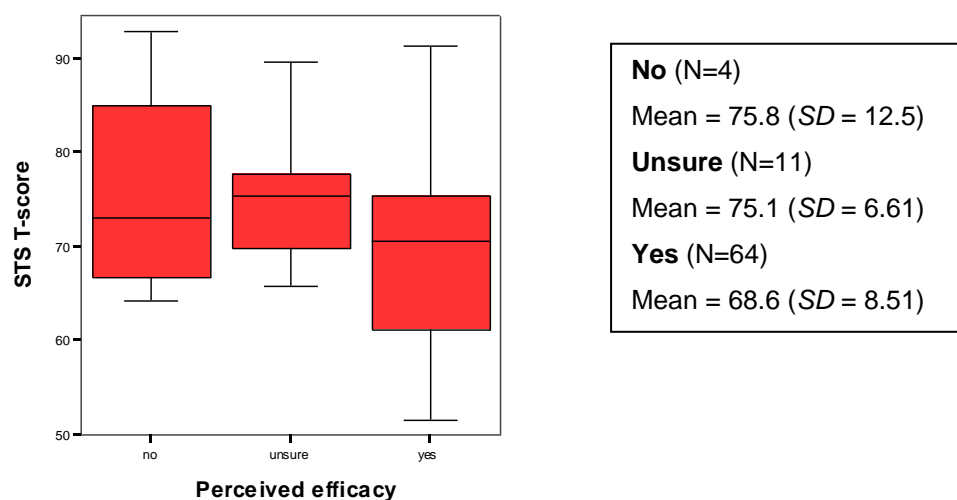
unsure (Figure 4.23 below).

Figure 4.23 Compassion Satisfaction by Perceived Efficacy



There were no significant differences in mean levels of Burnout between the three groups, $F(2, 77) = 2.074$, $p = .133$. However, there was a significant systematic difference in the mean levels of Secondary Traumatic Stress between the three groups, $F(2, 78) = 3.76$, $p = .028$, $\eta^2 = .09$. Caregivers who were unsure whether they were doing their work well had significantly higher levels of Secondary Traumatic Stress than those who thought they were doing a good job (see Figure 4.24 below).

Figure 4.24 Secondary Traumatic Stress by Perceived Efficacy



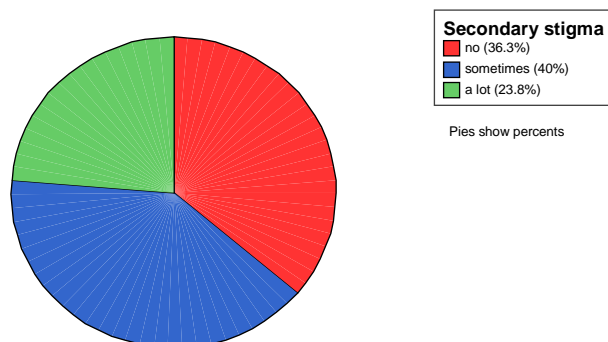
4.3.18 Referral mechanisms

All participants recorded a response to this item. An overwhelming majority (88%) indicated that they were satisfied that they knew where to refer clients for assistance that was beyond their scopes as caregivers. There were no significant differences in mean levels of the dependent variables between the three groups: for Compassion Satisfaction, $F(2, 81) = 0.359, p = .7$; Burnout, $F(2, 77) = 0.985, p = .378$; and Secondary Traumatic Stress, $F(2, 78) = 0.675, p = .512$.

4.3.19 Secondary stigma

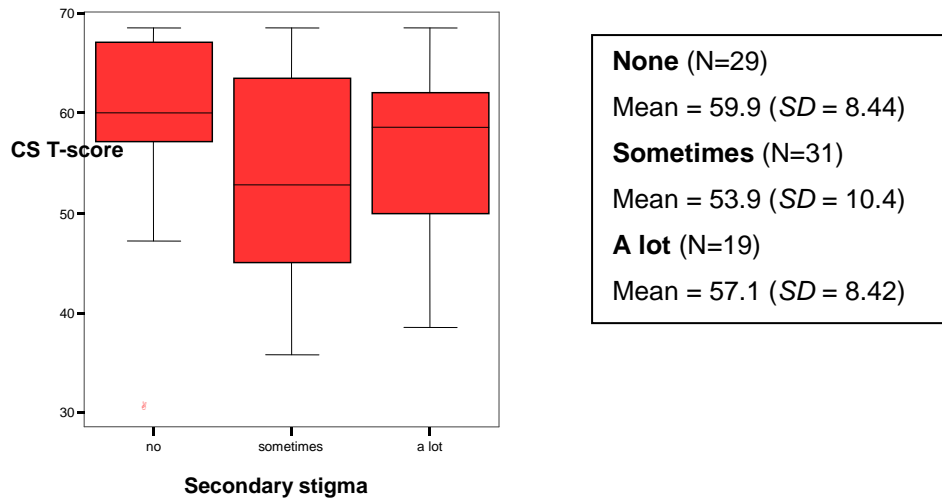
Three participants failed to indicate a response to this item. Of the 80 who did, 63.8% indicated that they were exposed to some level of secondary stigma as a result of their work as caregivers (see distribution in Figure 4.25 below)

Figure 4.25 Frequency Distribution – Secondary Stigma



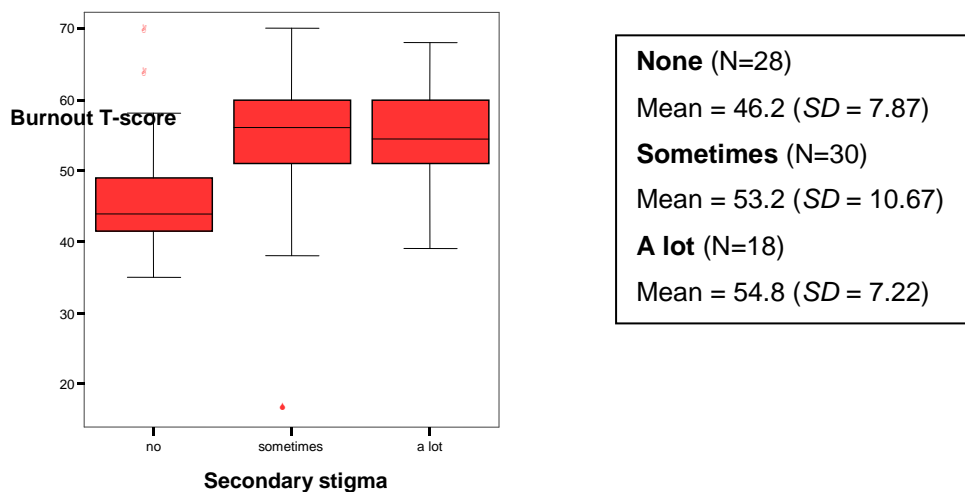
There was a significant systematic difference in levels of Compassion Satisfaction between caregivers who experienced no stigmatisation, those who experienced some stigmatisation and those who experienced a lot, $F(2, 78) = 3.14, p = .049, \eta^2 = 0.0763$. Those who experienced no stigma as a result of their work had significantly higher levels of Compassion Satisfaction than those who sometimes experienced stigma (Figure 2.26 below).

Figure 4.26 Compassion Satisfaction by Secondary Stigma



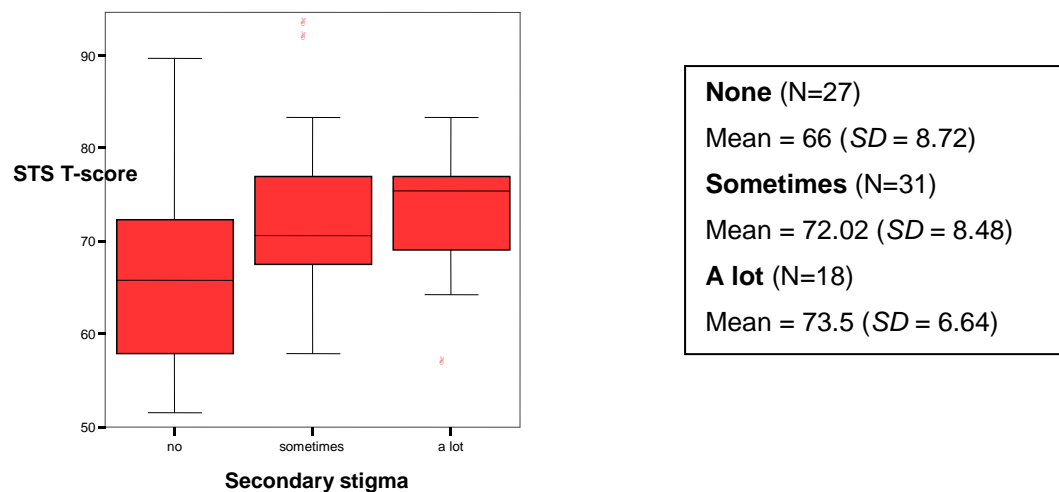
For Burnout, there was a significant systematic difference in mean levels between the three groups, $F(2, 75) = 6.47$, $p = .003$, $\eta^2 = 0.151$. Those who experienced no stigma as a result of their work had significantly lower levels of Burnout than those who experienced some and those who experienced a lot (Figure 4.27 below).

Figure 4.27 Burnout by Secondary Stigma



There was also a significant systematic difference in levels of Secondary Traumatic Stress between the three groups, $F(2, 75) = 5.77$, $p = .005$, $\eta^2 = 0.137$. Those who experienced no stigma had significantly lower levels of Secondary Traumatic Stress than those who experienced some and those who experienced a lot of stigma as a result of their work (Figure 4.28 below).

Figure 4.28 Secondary Traumatic Stress by Secondary Stigma

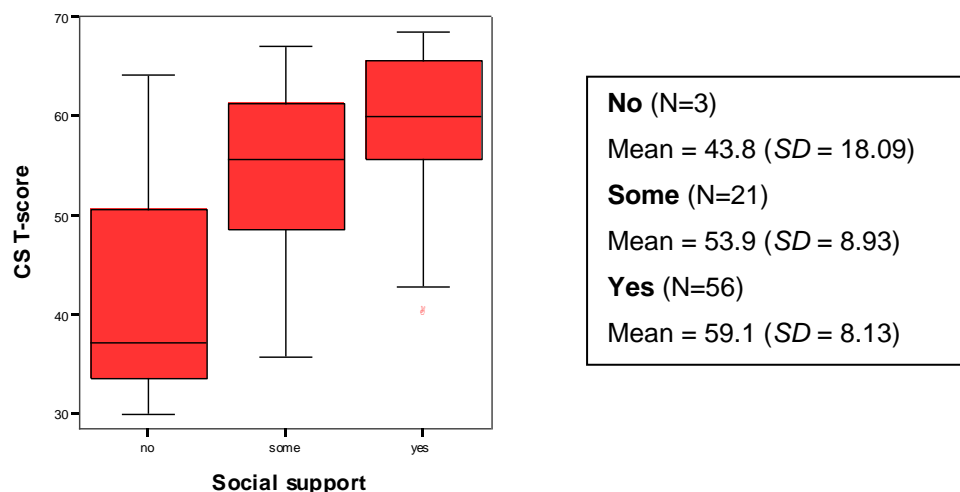


4.3.20 Social support

Two participants did not respond to this item. Of the 81 respondents, only 3 reported that they did not usually receive any support or encouragement from those close to them. Most (70.4%) reported that they were consistently supported by friends and family (refer to Table 4.6 for frequency distribution).

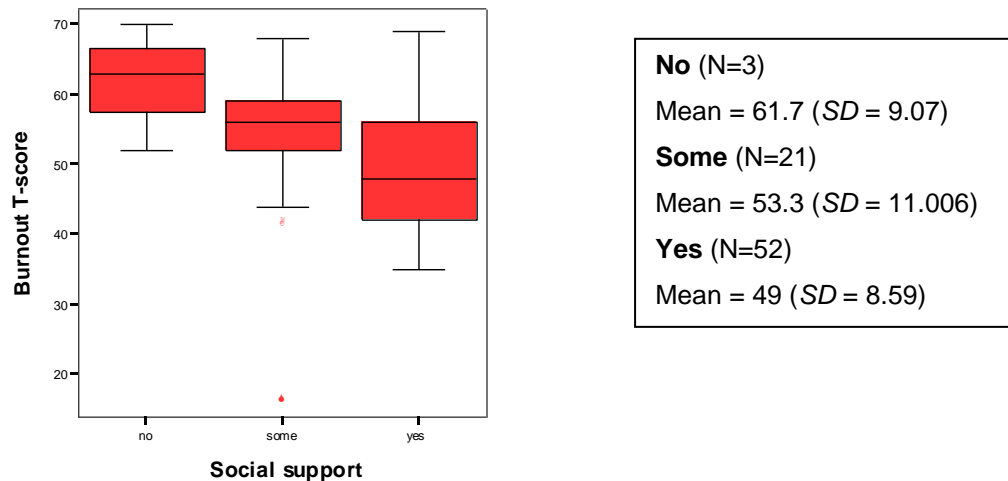
There was a significant systematic difference in mean levels of Compassion Satisfaction between the three groups, $F(2, 79) = 6.37, p = .003, \eta^2 = 0.142$. Both caregivers who reported receiving no support and those who received it inconsistently had significantly lower levels of Compassion Satisfaction than those who had consistent support (Figure 4.29 below).

Figure 4.29 Compassion Satisfaction by Social Support



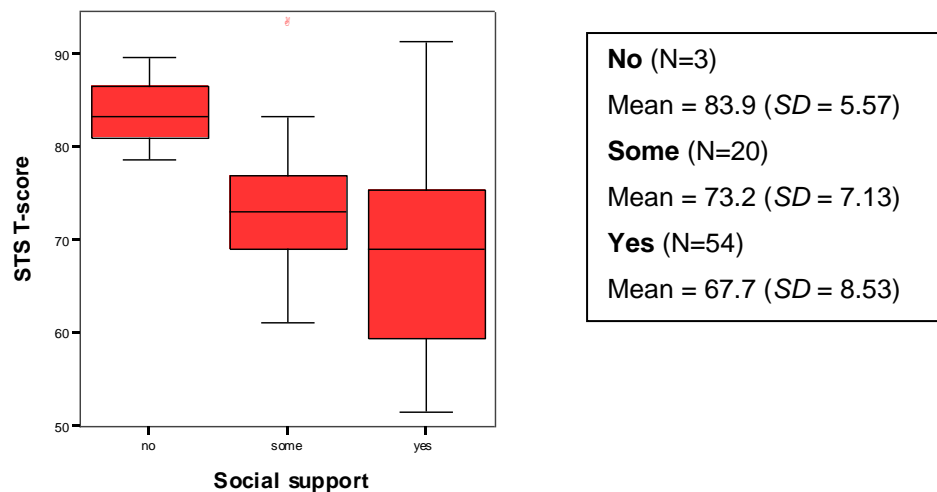
There was a significant systematic difference in mean levels of Burnout between the three groups, $F(2, 75) = 3.78$, $p = .027$, $\eta^2 = 0.0942$. Caregivers who reported consistent social support had significantly lower levels of Burnout than those who received none (see Figure 4.30).

Figure 4.30 Burnout by Social Support



There was also a significant systematic difference in mean levels of Secondary Traumatic Stress between the groups, $F(2, 76) = 7.98$, $p = .001$, $\eta^2 = 0.177$. Caregivers who reported consistent support from those close to them had significantly lower levels of Secondary Traumatic Stress than those who received support only sometimes and those who received none (see Figure 4.31).

Figure 4.31 Secondary Traumatic Stress by Social Support

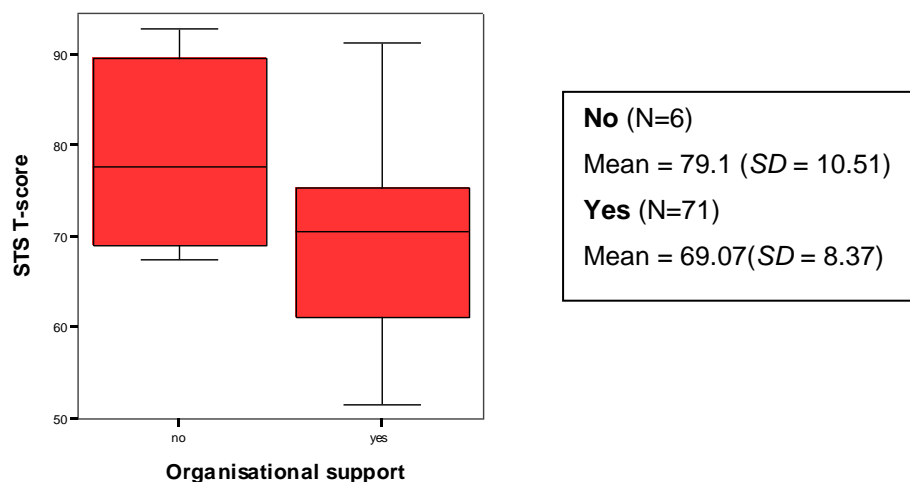


4.3.21 Organisational support

Two participants did not respond to this item. An overwhelming majority of the 81 respondents (92.6%) indicated that they did receive help and advice relating to their work from somebody within the organisation they work with.

There were no significant differences in mean levels of Compassion Satisfaction, $t(78) = -1.15$, $p = .252$, or Burnout, $t(5.18) = -0.537$, $p = .614$, between caregivers with organisational support and those without. However there was a significant difference in mean levels of Secondary Traumatic Stress between the two groups, $t(75) = 2.77$, $p = .007$, $d = 1.176$ (see Figure 4.32 below). Caregivers who reported that they did not receive support from within their organisation had higher levels of secondary traumatic stress than their counterparts who did have support.

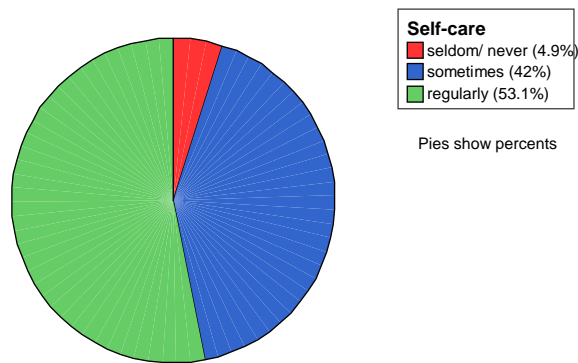
Figure 4.32 Secondary Traumatic Stress by Organisational Support



4.3.22 Self-care

Two participants did not respond to this item. As shown in Figure 4.33, slightly over half of respondents (53.1%) indicated that they regularly engage in activities that helped them to relax and feel good.

Figure 4.33 Frequency Distribution – Self-care



There were no significant systematic differences between the three groups in mean levels of Compassion Satisfaction, $F(2, 79) = 1.48$, $p = .234$, or Burnout, $F(2, 75) = 0.301$, $p = .741$.

There was a significant systematic difference in mean levels of Secondary Traumatic Stress, $F(2, 76) = 3.72$, $p = .029$, $\eta^2 = 0.091$. Caregivers who engaged in regular self-care had significantly lower levels of Secondary Traumatic stress than those who did so seldom or never (see Figure 4.34 below).

Figure 4.34 Secondary Traumatic Stress by Self-Care



4.4 Summary

This chapter has presented the results of the statistical analysis performed on the data collected in this study. The following represents a summary of the main findings, which will be discussed further in the next chapter.

4.4.1 Mean levels of dependent variables

It was found that respondents' mean scores on the dependent variables, namely Compassion Satisfaction, Burnout and Secondary Traumatic Stress, corresponded with the 73rd, 50th and 95th percentile of the reference norm group respectively. This indicates an overall pattern of relatively high Compassion Satisfaction, an average level of Burnout, and a very high level of Secondary Traumatic Stress among respondents.

4.4.2 Compassion Satisfaction

In the case of Compassion Satisfaction, highly significant negative correlations existed with Burnout, $r(75) = -.536, p < .0005$, and Secondary Traumatic Stress, $r(76) = -.410, p < .0005$. Significant differences in levels of Compassion Satisfaction were found at different levels of the following independent variables: (1) gender; (2) role clarity; (3) perceived efficacy; (4) secondary stigma; and (5) social support. The largest effect sizes were found with role clarity and social support.

4.4.3 Burnout

A highly significant positive correlation existed between Burnout and Secondary Traumatic Stress, $r(72) = .456, p < .0005$. Statistically significant differences in mean levels of Burnout were found at different levels of the following independent variables: (1) gender, (2) role clarity, (3) secondary stigma, and (4) social support. The largest effect sizes were found with role clarity and secondary stigma.

4.4.4 Secondary Traumatic Stress

In addition to the correlations reported above, significant differences in levels of Secondary Traumatic Stress were found at different levels of the following independent variables: (1) personal history of HIV or AIDS; (2) access to counselling or therapy; (3) role clarity; (4) perceived efficacy; (5) secondary stigma; (6) social support (7) organisational support; and (8) self-care. The largest effect sizes were found with role clarity, social support, organisational support and secondary stigma.

CHAPTER 5 – DISCUSSION

5.1 Introduction

The findings reported in the previous chapter suggest that a number of the personal attributes investigated in this study have significant relationships with caregivers' levels of compassion satisfaction, burnout and compassion fatigue. In this chapter, these findings are discussed further and integrated with existing literature. The demographic and professional quality of life profiles of the caregivers in this study are considered, with reference to both previous research and their implications for the sustainable provision of care to people affected by HIV and AIDS. Some key limitations and shortcomings of this study are also examined.

5.2 Demographic profile of caregivers

The demographic profile of caregivers in this study mirrors those in previous research in a number of ways. The overwhelming majority of the respondents were single women volunteers, most of whom were either unpaid or received only a stipend as compensation for their work. The findings of this study are therefore congruent with assertions that the burden of care for people infected and affected by HIV rests largely on women who have limited access to resources (Armstrong, 2000; Marais, 2006; Steinberg et al., 2002; Thabethe, 2006; United Nations Secretary-General's Task Force on Women, Girls and HIV/AIDS in Southern Africa, 2004). Mpophomeni, the peri-urban community from which many of the participants in this study were drawn, has high rates of unemployment, and accessing financial resources is often problematic for community-based organisations working in the area (Mathambo & Richter, 2007).

5.2.1 Age

The ages of respondents varied widely, with the youngest caregiver aged 20 and the oldest 75. However, with a mean age of 33, the overall age profile of respondents seems to parallel that of the people who are most affected by AIDS. A large scale household survey found that over two thirds (64%) of people sick with AIDS were women aged on average 33 years old (Steinberg et al., 2002). Although no significant

effects for identification with clients were found in this study, the significantly higher level of secondary traumatic stress among caregivers with personal links to HIV and AIDS could be explained in part by this parallel. Most respondents (57%) indicated that either they or somebody close to them had been directly affected by HIV and AIDS, and previous research suggests that many caregivers are either caring for someone within their own families or are HIV positive themselves (Armstrong, 2000; Mathambo & Richter 2007). As stated in Chapter 2, witnessing the disease process in clients may provoke anxiety and fear regarding one's own future (DeCarlo & Folkman, 1997), and this seems particularly likely when clients and caregivers share similar demographic profiles (Houghton & Christensen, 2006).

5.2.2 Education

There was a high overall level of scholastic education among respondents and the overwhelming majority (91.43 %) had engaged in some form of further training, at least at certificate level. However, despite this, most caregivers were not engaged in formal employment. This reflects the prevalence of unemployment in the wider community, which in 2001 reportedly stood at 34% in the uMngeni municipal area, with higher levels in Mpophomeni itself (uMngeni Municipality, 2011).

5.2.3 Experience and training

These varied widely between the respondents. However, most respondents reported having had only three weeks training, and more than half indicated that they felt the need to increase their knowledge in the light of the demands of their work. These findings highlight the importance of providing caregiver training on an ongoing basis. The modal response for experience was two years, which seems to reflect the pattern of high attrition among South African home-based carers noted in previous research (Akintola, 2004). However, a substantial proportion of caregivers indicated experience of five years or more.

5.3 Professional quality of life – profile of respondents

Mean levels on the ProQOL subscales suggest an overall pattern of relatively high Compassion Satisfaction, an average level of Burnout, and a very high level of Secondary Traumatic Stress among respondents.

In the manual's guidelines for interpreting subscale scores in combination, the profile that most closely resembles the above pattern is defined as "high Secondary Traumatic Stress and high Compassion Satisfaction with low Burnout" (Stamm, 2009, p.23). According to Stamm, this combination is typically only found among people working in high risk contexts such as armed conflict. People with this score profile are described as highly effective in their work as a result of their perception that their work is valuable; however, as individuals they are likely to have high levels of fear as a consequence of their secondary exposure to trauma. Stamm advises that people with this score profile be encouraged to build on their perceptions of making a positive contribution, but cautions that their symptoms of traumatic stress also need to be addressed. Encouragingly, she claims that brief interventions are often effective in such cases (Stamm, 2009).

The finding that the professional quality of life profile of caregivers resembles those of people working in war situations points to the fact that the challenges and emotional demands of this work should not be underestimated. Clearly, although caregivers can and in many cases do derive reward and satisfaction from their work, it is also a heavy burden with potentially serious implications for their personal, relational and social functioning outside of the work context (Figley, 1995; Rudolph, Stamm & Stamm, 1997; Stamm, 1997). The high levels of secondary traumatic stress evident among caregivers in this study indicate that intervention should be considered a matter of priority. Apart from the high personal cost to the caregivers themselves, it suggests significant consequences for the continued provision of care to people affected by HIV and AIDS. Fortunately, as previously stated, compassion fatigue is highly amenable to treatment (Figley, 2002).

This study found significant negative correlations between compassion satisfaction and burnout, and compassion satisfaction and secondary traumatic stress (compassion fatigue). These correlations are much stronger than those reported in the test manual, suggesting an effect specific to this study rather than owing to the construction of the measure. Staines (2000) similarly reports significant negative correlation between Compassion Satisfaction and Secondary Traumatic Stress subscale scores. These findings suggest that the feelings of making a difference, self-efficacy and meaning that are associated with higher levels compassion satisfaction may mitigate the

distressing aspects of caregiving, and therefore act as a buffer against burnout and compassion fatigue. This is congruent with Pines' (2000) psychodynamic existential theory of the aetiology of burnout, in which failure to find meaning in one's occupation is central; and also with Stamm's (2002) suggestion that personal resilience may be increased by the perception of making a difference through one's work.

A significant positive correlation was found between burnout and secondary traumatic stress. Interestingly, however, the strength of this correlation appeared smaller than that reported in the manual, which reports 34% covariance between the two subscales (Stamm, 2009). The scale's author suggests that this reflects the negative affect and "distress that is common to both conditions" (Stamm, 2009, p. 13). An even stronger correlation between these two subscales has been reported in an earlier study (Deighton et al., 2007). In this instance, the researchers suggest that this could reflect a reciprocal relationship between the processes of burnout and secondary traumatic stress, which results in workers suffering from a cluster of symptoms of both (ibid.).

Although the mean level of burnout for respondents in this study was within the average range, it is noteworthy that over a quarter (28.2%) had scores that indicate a high risk of burnout. Given the potential effects of burnout on both an individual level and in terms of work performance and quality, this should be regarded as highly concerning. According to the scale's author, "people who score high on burnout, in any combination with the other [sub]scales, are at risk as individuals and may also put their organizations in high-risk situations" (Stamm, 2009, p. 22).

5.4 Significant effects

5.4.1 Compassion satisfaction, burnout and secondary traumatic stress

Three attributes were found to have significant effects for all three aspects of professional quality of life. These attributes were (1) role clarity, (2) social support, and (3) perceived stigma.

5.4.1.1 Role clarity

With regard to role clarity, the results of this study indicate that being sure of the extent and limits of the caregiver's role is associated with lower levels of burnout and secondary traumatic stress, and higher levels of compassion satisfaction. It is possible that lacking clarity on the role of caregivers is associated with role overload, which has been identified as a cause of stress and burnout in literature (Crook et al., 2006). Being uncertain of the boundaries of their role might lead to caregivers taking on more responsibilities than they can reasonably handle, resulting in their work becoming a source of considerable stress and little satisfaction because of seemingly unending demands and a continual sense of never having done enough.

For all three dependent variables approximately 20% of the total variance was accounted for by differences between the groups, indicating that role clarity had one of the strongest effects of all the attributes investigated. An examination of the frequency distribution reveals that almost half of respondents (49, 4%) indicated that they felt uncertain of the boundaries of their roles to some degree. It therefore seems prudent for organisations to define explicitly what the role of caregiver does and does not entail, which would provide both caregivers and their clients with clarity in this regard. However, this should be done in a collaborative way with the caregivers themselves, rather than imposed by the management structure. This would be advantageous in that it would encourage a sense of ownership of the role on the part of the caregivers, and because of the importance of consultation and collaboration in the prevention of burnout (Maslach & Leiter, 1997; Miller, 2000).

5.4.1.2 Social support

The second personal factor for which significant effects were found in compassion fatigue, burnout and secondary traumatic stress was social support. Good social support networks have been highlighted as central to the prevention of compassion fatigue (Figley, 2002; Miller, 2000; Yassen, 1995). However, once present, compassion fatigue often leads to feelings of alienation and disconnection from colleagues as well as friends and family (Stamm, Varra, Pearlman & Giller, 2002). This suggests that the relationship between the two could consist of a self-perpetuating cycle in which compassion fatigue prevents people from accessing or maintaining networks of support, and poor support in turn entrenches processes and

symptomatology associated with compassion fatigue.

5.4.1.3 Secondary stigma

Caregivers who did not perceive themselves as being stigmatised by their work had higher levels of compassion satisfaction and lower levels of burnout and secondary traumatic stress than their peers. As is evident from the frequency distribution, most respondents also indicated that they do perceive themselves as stigmatised to some degree by their caregiving work. The process of social contagion whereby caregivers become stigmatised through their work with people with HIV and AIDS has been well-documented in previous research (Armstrong, 2000; Demmer, 2006; Miller, 2000), and has also been identified as a factor which adds to their work-related distress (Miller, 2000; Orner, 2006; Richter et al., 1996; Thabethe, 2006). The findings of the current study lend additional support to this contention, and further suggests that exposure to secondary stigma is associated with experiencing lower levels of satisfaction and reward in relation to caregiving work. Secondary stigma should also be considered as a factor which could negatively affect caregivers' potential social support due to its potentially marginalising effect.

5.4.2 Compassion satisfaction and burnout

Gender had significant effects for both of the above aspects of professional quality of life. It is of interest that male caregivers were found to have lower levels of compassion satisfaction and higher levels of burnout than their female counterparts. This contrasts with research findings in other contexts, where no differences were found between sexes on any of the ProQOL subscales (Deighton et al., 2007, Stamm, 2009). As has been noted, as a result of the gender imbalance among caregivers the total number of male participants in this study was quite low. To adequately explore whether the above finding reflects a wider trend would therefore require further research with a larger sample of male participants. However, some tentative explanations for the above discrepancy (based on the theories of burnout discussed in Chapter 2) are suggested below.

The social learning perspective implicates the establishment and maintenance of unrealistic personal goals, which are maintained despite negative situational feedback

(McCann & Pearlman, 1990). It seems plausible that having unrealistic goals might suggest an inadequate appreciation of the boundaries of the caregiving role. An examination of individual responses to the questionnaire item on role clarity suggests this may be a possibility in the case of male caregivers, as the modal response of men to this item was some uncertainty regarding the extent and limits of their roles, while for women the modal response was certainty in this regard.

A psychosocial approach to burnout implicates the interaction of individual characteristics with organisational and social contexts (Farber, 2000). This suggests that men are exposed to specific environmental stressors in their caregiving role. Here it might be relevant that male caregivers are in effect acting in opposition to the traditional gender roles and divisions of labour in their communities (Akintola, 2004; Mathambo & Richter, 2007). This could conceivably also impact negatively on the amount of recognition and satisfaction they derive from their work.

For a more equitable distribution of the caregiving burden in the longer term, it is important that these possibilities are investigated through further research.

5.4.3 Compassion satisfaction and secondary traumatic stress

Caregivers' perceived efficacy had significant effects for the above two dependent variables. In the case of compassion satisfaction, it was found that caregivers who perceived themselves as effective had higher levels of compassion satisfaction than their counterparts who felt unsure of their efficacy. However, the mean level of compassion satisfaction among caregivers who perceived themselves as ineffective was not significantly lower than those who felt they were doing their work well. It should however be noted that the number of caregivers who indicated that they felt they were not doing their work well was very small ($N = 4$). To draw a more definite conclusion about the effects of perceived efficacy on compassion satisfaction would require a comparison with greater power, involving a larger group of caregivers who perceived themselves as ineffective.

5.4.4 Secondary traumatic stress

Four personal attributes were found to have significant effects for secondary traumatic stress only, namely (1) personal history of HIV or AIDS; (2) self-care; (3) access to counselling and therapy; and (4) organisational support.

5.4.4.1 Personal history of HIV or AIDS

As stated above, most respondents indicated a personal link to HIV and AIDS over and above their work. A possible contributing factor to the higher levels of secondary traumatic stress among caregivers with a personal connection to the virus may be the fear and anxiety over their own futures elicited by working with clients who are similar to themselves, especially when caregivers themselves are HIV positive (see 5.2.1 above).

5.4.4.2 Self-care

The negative relationship between levels of secondary traumatic stress and self-care found among respondents in this study seems likely to be bidirectional in nature. As noted in chapter two, people affected by compassion fatigue are likely to neglect self-care (Smith, 2007; Stamm, Varra, Pearlman & Giller, 2002); yet good self-care is also an important factor in its prevention (Figley, 2007). Despite research supporting the key role of self-care strategies, this area may be accorded insufficient attention in caregiver training programmes (Thabethe, 2006). It is therefore recommended that self-care strategies should be incorporated into ongoing training provided to caregivers. Some funders have in the past viewed resources allocated to self-care as unnecessary expenditure (Armstrong, 2000). However, it seems that good self-care has an important relationship with caregivers' well-being and resilience, with consequences for both the quality of the care they render to clients and their retention as caregivers over the longer term.

5.4.4.3 Access to counselling/ therapy

There was a fair overall level of access to counselling or therapy among caregivers, with slightly over half (54, 2%) reporting that they are able to obtain this assistance if they feel they require it. However, in light of the challenging nature of caregiving work and its capacity to impact on the emotional well-being of caregivers, it is concerning that a substantial proportion of the caregivers reported being unable to

access this help, particularly as the results of this study support the existence of a relationship between access to counselling or therapy and lower mean levels of secondary traumatic stress. Attention to the emotional health of care workers has been identified as important in reducing their vulnerability to the potential negative sequelae of their work (Houghton & Christenson, 2006; Rudolph, Stamm & Stamm, 1997; Staines, 2000). Access to counselling and therapy should therefore be considered as part of interventions to prevent and treat compassion fatigue and burnout.

5.4.4.4 Organisational support

The majority of respondents indicated that they did receive organisational support in the form of help and advice relating to their work with clients. The minority of caregivers who reported that they did not had significantly higher levels of secondary traumatic stress than their peers. This finding is supported by literature which emphasises the importance of consultation and supervision in the prevention of compassion fatigue and burnout (Miller, 2000; Rudolph, Stamm & Stamm, 1997; Stamm et al., 2002; Uys, 2002).

5.5 Limitations and shortcomings of the study

There were a number of limitations and shortcoming in this study. Firstly, the data in this study was collected through self-report measures. The point has been made that although this method rests on the assumption that respondents will answer items accurately, this is not always the case (Hammond, 2006). Response bias can originate from a number of sources, including (1) a wish to present oneself in a favourable light, (2) not understanding the question, (3) a lack of self-knowledge, and (4) random answering or response sets (ibid.). In this context, it may also be relevant that literature suggests that women caregivers are hesitant to voice their problems due to socio-cultural norms about gender roles (Akintola, 2004).

Secondly, the questionnaire regarding caregivers' personal attributes relied on only one item to gauge each attribute. Additionally, the attributes investigated by this questionnaire were derived from existing literature; and it should be noted that there may be other context specific factors that have significant relationships to compassion

satisfaction, burnout and compassion fatigue among caregivers which were not identified in this study.

During the data collection phase of this study, a research assistant was available to assist participants with reading and completing questionnaires on request. However, it became evident that although some participants had difficulties in this regard, they did not always ask for help. Low levels of functional literacy among some respondents appeared to contribute to the high number of incomplete or unscorable questionnaires which were excluded from the dataset, resulting in an unintentional bias.

Finally, it should be noted that the design of this study does not permit for the investigation of causality. Thus, although it may be established that there is a relationship between a particular personal attribute and compassion satisfaction, burnout, or compassion fatigue; it is not possible to conclude that modification of the attribute concerned will lead to a corresponding change in professional quality of life.

5.6 Summary

The demographic characteristics of caregivers who took part in this study indicate that most were women from socially disadvantaged contexts. This finding is similar to those of earlier research, and has implications for the sustainability of community care programmes. Overall, caregivers had high levels of compassion satisfaction, average levels of burnout and very high levels of secondary traumatic stress. This profile is usually associated with people working in situations characterised by danger of physical violence. Caregivers need to be encouraged to build on their feelings of altruism and making a difference, but intervention is required to address high levels of compassion fatigue, as this has serious consequences in terms of social and occupational functioning. The findings of this study indicate that a number of personal attributes do have relationships with compassion satisfaction, burnout and secondary traumatic stress; these are discussed in detail above. Shortcomings and limitations of this research stemming from the methodology and design include the use of self-report data and the fact that it did not allow for the determination of causality between variables.

CHAPTER 6 – CONCLUSIONS AND RECOMMENDATIONS

6.1 Introduction

This chapter presents conclusions, recommendations and directions for further research prompted by the results of the current study.

6.2 Equity and sustainability

Issues of gender and power relations are clearly an inextricable part of the issue of caregiving in South Africa. It has been pointed out that home-based care is central in the provision of HIV and AIDS care, and that it in effect subsidises the burden on the public healthcare system and wider economy (Uys, 2002; Marais, 2006). The fact that this burden is essentially being borne in the main part by poor women should be a matter of grave concern, not only from a social justice perspective, but because it raises questions about the sustainability of the provision of care over the longer term (Marais, 2006). Research should be directed towards finding solutions which would see this burden more equitably distributed in our society.

While the mean experience of caregivers in this study is comparatively brief (two years), some participants have been involved in this work for periods of eight years and more. It is suggested that a future direction for research would be to investigate what factors have contributed to caregivers such as these being able to stay in the field for such extended periods. This knowledge could be useful in informing future interventions aimed at increasing the resilience of caregivers, and to counteract attrition as a result of compassion fatigue and burnout. Qualitative methods of research would seem most suitable, in order to explore in depth and identify factors which may be context-specific.

6.3 Secondary traumatic stress/ compassion fatigue

The very high level of secondary traumatic stress among participants in this study is of serious concern, and indicates the need for intervention as a matter of priority. However it is important that compassion fatigue should not be seen as a personal problem, but as natural consequence working with traumatised people (Figley, 1995). More research is needed to explore the extent of compassion fatigue among caregivers of people affected by HIV and AIDS in South Africa as a whole. A potential direction

for research could be evaluating the efficacy of intervention programmes by using the ProQOL.

6.4 Burnout

Notably, more than a quarter of the participants in this study scored in the upper range of the burnout scale, indicating that this represents a problem for a sizable group of caregivers. Research suggests that burnout should be viewed as arising from problems with the work environment, specifically high work-loads and dysfunctional systems (Maslach & Leiter, 1997; Stamm, 2009). It is therefore recommended that organisations in this field need to be aware of burnout as a potential problem, and structure their operations in ways that enhance caregiver support.

6.5 Compassion satisfaction

Compassion satisfaction appears to have an inverse relationship with both compassion fatigue and burnout, which suggests that the degree of personal reward and fulfilment associated with caregiving may serve a protective function. This has potential implications for prevention and treatment of compassion fatigue and burnout, and it is suggested that this is a direction for further research.

6.6 Role clarity

Interventions to further define and explicate the role of caregiver are needed. It is recommended that this is done as part of a consultative process, and that the boundaries of the caregiving role are made clear to all concerned, including clients and their families.

6.7 Secondary stigma

The results of this study imply that interventions to reduce stigmatisation of people with HIV and AIDS would also benefit those who care for them, as most respondents reported being exposed to secondary stigma as a result of their work with people affected by HIV and AIDS. In addition to interventions to reduce stigmatisation, it is recommended that organisations equip caregivers with resources to increase their resilience in the face of secondary stigma, particularly as this study suggests that it is related to both the positive and negative sequelae of caregiving work.

6.8 Male caregivers

The gender discrepancy for levels of compassion satisfaction and burnout evident in this study suggests that further investigation and research among male caregivers is indicated. A larger and more representative sample would be needed to establish if this discrepancy reflects a wider trend or is specific to this study. Qualitative research could be useful in identifying and exploring possible contextual factors that might lead to male caregivers deriving comparatively little satisfaction from their work and also increase their vulnerability to burnout. Such research is of importance because to make community care for people with HIV and AIDS sustainable over the longer term requires that the burden of care is more equitably distributed, as stated above. Exploring factors that might discourage the involvement of men in caregiving work could therefore inform interventions to accomplish this objective.

6.9 Organisational considerations

It is recommended that programmes to prevent compassion fatigue and burnout among caregivers are developed and implemented. The provision of quality supervision and consultation should be considered as part of prevention, as this study indicates this has a relationship with lower levels of secondary traumatic stress. Peer support groups could provide a further resource in dealing with the challenges of caregiving.

Secondly, there is a need for ongoing training among caregivers, and this should incorporate education about compassion fatigue and burnout, as well as strategies for self-care and coping. Particular emphasis should also be placed on the importance of maintaining good social support networks.

Finally, access to counselling and therapy for caregivers needs to be expanded. The results of this study indicate is a relationship between the ability to access this form of help when needed and lower levels of secondary traumatic stress.

References

- Akintola, O. (2004). *The gendered burden of home-based care-giving*. Policy brief: Health economics and HIV/ AIDS research division, University of KwaZulu-Natal. Retrieved January 21, 2008, from <http://allafrica.com/sustainable/resources/view/00010373.pdf>
- Armstrong, S. (2000). *Caring for carers: Managing stress in those who care for people with HIV and AIDS*. Geneva: Joint United Nations Programme on AIDS (UNAIDS). Retrieved May 10, 2008, from http://data.unaids.org/Publications/IRC-pub02/jc717-caringcarers_en.pdf
- Bodibe, K. (2010, September 9). The link between mental health & HIV [Living with AIDS #447]. *Health-e News Service*. Retrieved September 9, 2010, from http://www.health-e.org.za/news/easy_print.php?uid=20032919
- Bride, B. E., Radey, M., & Figley, C. R. (2007). Measuring compassion fatigue. *Clinical Social Work Journal*, 35(3), 155-163.
- Brown, F. M. (2002). Inside every chronic patient is an acute patient wondering what happened. *Journal of Clinical Psychology/ In Session: Psychotherapy in practice*, 58(11), 1443-1449.
- Centers for Disease Control and Prevention. (2002). Drug-associated HIV transmission continues in the United States. Retrieved June 1, 2010, from <http://www.thebody.com/content/art17240.html>
- Cournos, F., & Collins, P. (2003). A view of HIV/AIDS and mental health issues in South Africa – from the outside looking in. In M. Freeman (Ed.), *Mental health and HIV/AIDS: Report on a round table discussion, March 2003* (p. 21-27). Cape Town: HSRC Press. Retrieved May 17, 2010, from <http://www.hsrcpress.ac.za/product.php?productid=2003&freedownload=1>

- Cullinan, K. (2002). KZN hospitals under pressure. *Health-e News Service*. Retrieved May 17, 2010, from <http://www.csa.za.org/article/articleview/156/1/1/>
- Cullinan, K. (1999). AIDS martyr's killers may face justice. *City Press*, Sunday 26 September. Retrieved May 10, 2010, from <http://www.health-e.org.za/news/article.php?uid=19991105>
- DeCarlo, P., & Folkman, S. (1997). Are informal caregivers important in AIDS care? *Positive Outlook*, 4(2), 26-27.
- Deighton, R. M., Gurrus, N., & Traue, H. (2007). Factors affecting burnout and compassion fatigue in psychotherapists treating torture survivors: Is the therapist's attitude to working through trauma relevant? *Journal of Traumatic Stress*, 20(1), 63-75.
- Demmer, C. (2006). Caring for a loved one with AIDS: A South African perspective. *Journal of Loss and Trauma*, 11, 439-455.
- Farber, B. A. (2000). Introduction: Understanding and treating burnout in a changing culture. *Journal of Clinical Psychology/ In Session: Psychotherapy in Practice*, 56(5), 589-594.
- Figley, C. R. (1995). Compassion fatigue as secondary traumatic stress disorder: An overview. In C. R. Figley (Ed.), *Compassion fatigue: Coping with secondary traumatic stress disorder in those who treat the traumatized*, pp.1-20. New York: Brunner-Routledge.
- Figley, C. R. (2002). Compassion fatigue: Psychotherapists' chronic lack of self care. *Journal of Clinical Psychology/ In Session: Psychotherapy in Practice*, 58(11), 1433-1441.
- Figley, C. R. (2003). *Compassion fatigue: An introduction*. Retrieved May 13, 2010, from <http://www.giftfromwithin.org/html/cmpfatig.html>

- Figley, C. R. (2007). *The art and science of caring for others without forgetting self-care*. Retrieved May 13, 2010, from <http://www.giftfromwithin.org/html/artscien.html>
- Freeman, M., Patel, V., Collins, P. Y., & Bertolote, J. M. (2005). Integrating mental health in global initiative for HIV/AIDS. *British Journal of Psychiatry*, 187, 1-3.
- Freeman, M. (2003). Conclusions. In M. Freeman (Ed.), *Mental health and HIV/AIDS: Report on a round-table discussion, March 2003* (p. 60). Cape Town: HSRC Press.
- Gothan, D. L. (2003). *The motivation to volunteer: Factors prompting individuals offering psychosocial support to vulnerable children in KwaZulu-Natal*. Unpublished masters dissertation, University of KwaZulu-Natal, Pietermaritzburg.
- Hammond, S. (2006). Using psychometric tests. In G. M. Breakwell, S. Hammond, C. Fife-Schaw & J. A. Smith (Eds.), *Research methods in psychology* (3rd ed.), pp. 182-209. London: Sage.
- Injobo Nebandla (2005). *Freedom from strife? An assessment of efforts to build peace in KwaZulu-Natal*. Braamfontein: Centre for the Study of Violence and Reconciliation.
- King, J. (2002). *Care of the caregivers: Some practical measures*. Retrieved January 17, 2008, from <http://www.hivan.org.za/arttemp.asp?id=770>
- Lurie, M. N., Williams, B. G., Zuma, K., Mkaya-Mwamburi, D., Garnett, G. P., Sturm, A. W., Sweat, M. D., Gittelsohn, J., & Abdool Karim, S. S. (2003). The impact of migration on HIV-1 transmission in South Africa: A study of migrant and non-migrant men and their partners. *Sexually Transmitted Diseases*, 30(2), 149-156.
- Maslach, C., & Leiter M. P. (1997). *The truth about burnout: How organisations cause personal stress and what to do about it*. San Francisco: Jossey-Bass.

- Melamed, S., Shirom, A., & Toker, S. (2006). Burnout and risk of cardiovascular disease: Evidence, possible causal paths, and promising research directions. *Psychological Bulletin*, 132(3), 327-353.
- McCann, I. L., & Pearlman, L.A. (1990). Vicarious traumatization: A framework for understanding the psychological effects of working with victims. *Journal of Traumatic Stress*, 3(1), 131-149.
- Miller, D. (2000). *Dying to care? Work, stress and burnout in HIV/ AIDS*. London: Routledge.
- Moodley, K. (2001) *The influence of role-related stressors on educator burnout*. Unpublished masters dissertation, University of Natal, Pietermaritzburg.
- Orner, P. (2006). Psychosocial impacts on caregivers of people living with AIDS. *AIDS Care*, 18(3), 236-240.
- Pearlman, L. A., & Saakvitne, K. W. (1995). Treating therapists with vicarious traumatization and secondary traumatic stress disorders. In C. R. Figley (Ed.), *Compassion fatigue: Coping with secondary traumatic stress in those who treat the traumatized* (pp. 150-177). New York: Brunner/Mazel.
- Pines, A. (2000). Treating career burnout: A psychodynamic existential perspective. *Journal of Clinical Psychology/ In Session: Psychotherapy in Practice*, 56 (5), 633-642.
- Ramjee, G., & Gouws, E. (2002). Prevalence of HIV among truck drivers visiting sex workers in KwaZulu-Natal, South Africa. *Sexually Transmitted Diseases*, 29(1), 44-49.
- Richter, L., Durrheim, K., Griesel, D., & Solomon, V. (1999). *Evaluation of HIV/AIDS counselling in South Africa: Intervention linked research and pilot projects in the areas of HIV/AIDS care, counselling and support*. (Contract report

submitted to the Department of Health, South Africa, Tender No: RT 724 SP).
Pietermaritzburg: University of Natal, School of Psychology.

- Rudolph, J. M., Stamm, B. H., & Stamm, H. E. (1997). *Compassion fatigue: A concern for mental health policy, providers and administration*. Poster at the 13th annual meeting of the International Society for Traumatic Stress Studies, Montreal, CA.
- Sabin-Farrell, R., & Turpin, G. (2003). Vicarious traumatization: Implications for the mental health of health workers? *Clinical Psychology Review*, 23, 449-480.
- Sabo, B. M. (2006). Compassion fatigue and nursing work: Can we accurately capture the consequences of caring work? *International Journal of Nursing Practice*, 12, 136-142.
- Shisana, O., Rehle, T., Simbayi, L. C., Zuma, K., Jooste, S., Pillay-van Wyk, V., Mbelle, N., Van Zyl, J., Parker, W., Zungu, N. P., Pezi, S., & the SABSSM III Implementation Team (2009). *South African HIV national prevalence, incidence, behaviour and communication survey 2008: A turning tide among teenagers?* Cape Town: HSRC Press.
- Simbayi, L. C., Kalichman, S., Strebel, A., Cloete, A., Henda, N., & Mqeketo, A. (2007). Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa. *Social Science and Medicine*, 64(9), 1823-1831.
- Smith, B. D. (2007). Sifting through trauma: Compassion fatigue and HIV/AIDS. *Clinical Social Work Journal*, 35, 193-198.
- Spiegel, P. B., Bennedsen, A. R., Claass, J., Bruns, L., Patterson, N., Yiweza, D., & Schilperoord, M. (2007). Prevalence of HIV infection in conflict-affected and displaced people in seven sub-Saharan African countries: A systematic review. *The Lancet*, 369, 2187-2195.

- Staines, M. M. (2000). *Factors mediating the level of vicarious traumatization and compassion satisfaction*. Unpublished master's dissertation, University of Natal, Pietermaritzburg.
- Stamm, B. H. (1997). Work-related secondary traumatic stress. *PTSD Research Quarterly*, 8 (2), 1-3.
- Stamm, B. H. (2002). Measuring compassion satisfaction as well as fatigue: Developmental history of the compassion satisfaction and fatigue test. In C. R. Figley (Ed.), *Treating compassion fatigue*, pp. 107-119. New York: Routledge.
- Stamm, B. H. (2005a). *The professional quality of life scale: Compassion satisfaction, burnout and compassion fatigue subscales – Revision IV (ProQOL)*. Retrieved January 21, 2008, from <http://www.isu.edu/~bhstamm/tests.htm>
- Stamm, B. H. (2005b). *The ProQOL manual*. Retrieved January 21, 2008, from <http://www.isu.edu/~bhstamm/tests.htm>
- Stamm, B. H. (2009). *The Concise ProQOL Manual*. Pocatello, ID: ProQOL.org.
- Stamm, B. H., Varra, E. M., Pearlman, L. A., & Giller, E. (2002). *The helper's power to heal and to be hurt – or helped – by trying*. Register report: National Register of Health Service Providers in Psychology. Washington, DC. Retrieved April 27, 2008, from http://www.sidran.org/pdf/Helper's_Power_to_Heal.pdf
- Steinberg, M., Johnson, S., Schierhout, G., Ndegwa, D., Hall, K., Russell, B., & Morgan, J. (2002). *Hitting home: How households cope with the impact of the HIV/AIDS epidemic*. Washington, DC: The Henry J. Kaiser Family Foundation. Retrieved May 7, 2010, from <http://www.kff.org/southafrica/upload/Hitting-Home-How-Households-Cope-with-the-Impact-of-the-HIV-AIDS-Epidemic-Report.pdf>

- Thabethe, N. C. (2006). *Making connections: Towards a holistic approach to the training of women volunteers in community home based care*. Unpublished masters dissertation, University of KwaZulu-Natal, Durban.
- Thomas, F. (2006). Stigma, fatigue and social breakdown: Exploring the impacts of HIV/AIDS on patient and carer well-being in the Caprivi region, Namibia. *Social Science and Medicine*, 63, 3174-3187.
- uMngeni Municipality. (2011). *Housing development*. Retrieved January 2, 2011, from http://www.umngeni.gov.za/index.php?option=com_content&view=article&id=140&Itemid=227
- UNAIDS. (2008). *2008 report on the global AIDS epidemic*. Geneva: Joint United Nations Programme on HIV/AIDS.
- UNAIDS. (2008). *Preventing carer burnout: Inter-Mission Care and Rehabilitation Society (IMCARES): Highlights*. Geneva: Joint United Nations Programme on HIV/AIDS.
- United Nations Secretary-General's Task Force on Women, Girls and HIV/AIDS in Southern Africa. (2004). *Facing the future together: Report of the United Nations Secretary General's Task Force on Women, Girl's and HIV/AIDS in Southern Africa*. Retrieved January 17, 2008, from http://data.unaids.org/Publications/External-Documents-Restored/sgreport_facingfuture_en.pdf
- Uys, L. R. (2002). The practice of community caregivers in a home-based HIV/AIDS project in South Africa. *Journal of Clinical Nursing*, 11, 99-108.
- World Health Organisation (WHO). (2007). *International classification of diseases and related health problems, 10th revision (ICD-10)*, chapter XXI. Retrieved May 13, 2010, from <http://apps.who.int/classifications/apps/icd/icd10online/>

Worden, J. W. (2009). *Grief counselling and grief therapy: A handbook for the mental health practitioner* (4th ed.). London: Routledge.

Yassen, J. (1995). Preventing secondary traumatic stress. In C. R. Figley (Ed.), *Compassion fatigue: Coping with secondary traumatic stress disorder in those who treat the traumatized*, pp. 178-208. New York: Brunner-Routledge.

APPENDIX 1: ITEM ANALYSIS OF THE PROFESSIONAL QUALITY OF LIFE SCALE (PROQOL) VERSION 5 (STAMM, 2009)

Compassion Satisfaction subscale: Positive sequelae of helping others; that is, the pleasure derived from doing one's work well (Stamm, 2009).

- 3. I get satisfaction from being able to help people.
- 6. I feel invigorated after working with those I help.
- 12. I like my work as a caregiver.
- 16. I am pleased with how I am able to keep up with caregiving techniques and protocols.
- 18. My work makes me feel satisfied.
- 20. I have happy thoughts and feelings about those I help and how I could help them.
- 22. I believe I can make a difference through my work.
- 24. I am proud of what I can do to help.
- 27. I have thoughts that I am a "success" as a caregiver.
- 30. I am happy that I chose to do this work.

Burnout subscale: Negative sequelae of helping others, specifically those associated with a sense of futility and helplessness (Stamm, 2009).

- 1. I am happy. (Reverse scored)
- 4. I feel connected to other people. (Reverse scored)
- 8. I am not as productive in my work because I am losing sleep over traumatic experiences of a person I help.
- 10. I feel trapped by my work as a caregiver.
- 15. I have beliefs that sustain me. (Reverse scored)
- 17. I am the person I always wanted to be. (Reverse scored)
- 19. I feel worn out because of my work as a caregiver.
- 21. I feel overwhelmed because my workload seems endless.
- 26. I feel "bogged down" by the system.
- 29. I am a very caring person. (Reverse scored)

Secondary Traumatic Stress subscale: Negative sequelae of helping others, specifically those associated with fear and work-related trauma (Stamm, 2009).

- 2. I am preoccupied with more than one person I help.

- 5. I jump or am startled by unexpected sounds.
- 7. I find it difficult to separate my personal life from my life as a caregiver.
- 9. I think that I might have been affected by the traumatic stress of those I help.
- 11. Because of my caregiving work, I have felt “on edge” about various things.
- 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.
- 23. I avoid certain activities or situations because they remind me of painful experiences of the people I help.
- 25. As a result of my work as a caregiver, I have intrusive, frightening thoughts.
- 28. I can't recall important parts of my work with people affected by HIV and AIDS.

APPENDIX 2: DATABASE OF FACTORS THAT RESEARCH SUGGESTS MAY BE ASSOCIATED WITH LEVELS OF STS/ BURNOUT/ OCCUPATIONAL STRESS

Armstrong, 2000

- Realistic work targets, clear job descriptions and good referral mechanisms
- Regular time off that is respected
- Health care provision, paid sick leave
- Team work, and regular meetings where issues can be raised and problems discussed
- Appointment of counsellor for carers
- “Dispersal of emotional burden” - >1 person assigned to care for client
- Participation in decision making within programme

Crook, Weir, Willms & Egdorf, 2006

- Insufficient knowledge/ skills
- insufficient organizational resources
- Scheduling inflexibility
- Role overload (being expected to do more than possible)

Deighton et al. 2007

- Years of experience (protective effect for burnout, damaging on emotional exhaustion, no effect on VT and STS – p.65)
- Lack of supportive work environment
- Little trauma specific training and interpersonal resources
- Personal history of trauma (risk factor for high levels of STS, CF and burnout)
- “Fear avoidance” of clients' traumatic material/ not 'working through' clients' trauma, when low degree of working through was associated with high advocacy of doing so.
- Conflict between ideals and accomplishment (behaviour at odds with beliefs)
- Gender (no different)
- Number of clients seen per week (correlations with burnout, CF, emotional exhaustion, involvement, and work-related psychological distress – p. 68)

Figley, 2002

- Empathic response
- Disengagement – lowers/ prevents compassion stress. Refers to ability to distance self from client btw contacts and live own life.
- Self-care
- Sense of achievement (satisfaction with efforts to help)
- Prolonged exposure – increased risk. Deliberate breaks from being service provider important on reducing risk
- Traumatic recollections – When clients evoke memories of experiences with other clients, associated with emotional reaction
- Life disruptions (stressors) unrelated to work, which combine with work stress to increase risk.
- Social support system

Houghton & Christensen, 2006

- feelings of guilt and inadequacy
- dealing with the families of patients
- working with patients that carer identifies with
- feeling inadequately prepared to deal with multiple deaths of young people
- poor communication within organisation
- absence of structured feedback
- provision of staff support/ counselling
- ongoing training

Miller, 2000

- Dissatisfaction with training/ lack of training/ perceived inadequacy of training (Bennett, Ross & Sunderland, 1996; Guinan et al., 1991)
- Wanting to feel needed (risk factor)
- Feeling close to person cared for (risk factor)
- Age – younger age, greater risk (Claxton, Burgess & Catalan, 1993)
- Length of time spent as volunteer not related to risk, but number of people cared for was (Williams, 1986)
- Emotional overload
- Client problems for which volunteers felt inadequately prepared

- Tensions between paid staff/ professionals and volunteers (Bove et al., 1993; Patton, 1989).
- High levels of stigma in community
- Quality and level of supervision and support
- Shared ethos, support from colleagues
- Role clarity
- Choice over where to volunteer, how much time to spend in work and ability to withdraw from work
- Boundary clarification
- Sense of personal efficacy ((Bennett, Ross & Sunderland, 1996; Maslanka, 1996)
- Training, including recognising warning signs of stress and burnout
- Logistical support
- Appreciation, group solidarity between volunteers, and incentives.
- Intensity of contact with patients – sicker patients
- Grief (no relationship with burnout)
- Motivation – can lead to increased sense of reward AND greater vulnerability to negative psychological outcomes

Moodley, 2001

- Gender
- Age (inverse association with levels of burnout)
- Experience (conflicting findings, significant difference found among those with <4years experience and those with >4years, where less experience associated with higher levels of burnout).
- Marital status (burnout higher among single people)
- Education (positive correlation between burnout and education)
- Supervision
- Time pressure (feeling not enough – positive correlation with burnout)
- Dissatisfaction with salary (correlation not sig.)
- Role conflict (inability to meet variety of demands and expectations – sig. positive correlation)
- Role ambiguity (uncertainty about scope of responsibilities/ authority associated with job – sig. positive correlation)

- Role insufficiency (Inadequate supplies, equipment and/ or information, i.e. resources – sig. positive correlation with emotional exhaustion)
- Relationships with superiors and colleagues

Pearlman & Saakvitne, 1995

- History of trauma
- High ideals, rescue fantasies and over-investment
- Inadequate self-care
- Inadequate training in work with traumatised people
- Insufficient supervision by suitably trained supervisor
- Overidentification
- Sense of self (attending to own emotional, spiritual, psychological, and physical needs)
- Working in a climate of victim-blaming
- Working with clients who continue to be exposed to danger

Richter et al., 1996

- Training adequacy
- Institutional support
- Sufficient referral networks
- Adequacy of material resources, including transport
- Mentorship/ supervision
- Follow-up training and development
- Stigma and secrecy
- Organisational problems
- Clients with wide range of problems
- Support/ supervision groups

Rudolph, Stamm & Stamm, 1997

- Sex
- Level of training
- Personal history of trauma
- Education
- Well managed case load

- Access to internet and e-mail resources for consultation and information
- Adequate leave time
- Adequate health insurance, including mental healthcare
- Adequate supervision (clinical and administrative)

Sabin-Farrell & Turpin, 2003

- Empathic engagement
- Self-awareness (lower levels possible contributing factor to VT)
- Organizational context – setting, colleagues, caseload, supervision, and services offered to clients
- Social and professional climate
- Financial climate of the organisation
- Wider health care system
- Aspects of individual – coping mechanisms, personal history, current life context
- Current personal and professional circumstances
- Past trauma history
- Supervision (?)
- Group dynamics within organisation

Staines, 2000

- Gender (Norcross, Prochaska & DiClemente, 1986: women less VT; Horowitz, 1979: women endorsed more avoidance items on Impact of Life Events Scale, indicating significantly more subjective distress; Kassam-Adams, 1995: higher levels of PTSD symptoms among women).
- Age – negative correlation (Dutton & Rubenstein, cited in Figley, 1995)
- Social and family relationships (i.e. social support)
- Childhood and family of origin (levels of trauma, conflict, dysfunction)
- Personal history of trauma (conflicting findings in research)
- Personal therapy
- Engagement in coping behaviours
- Level of stigma they are exposed to as a result of their work
- Level of professional development (i.e. experience: inverse relationship)

- Caseload (moderate caseloads associated with less stress than light or heavy)
- Supervision
- Marital status
- Education and qualifications
- Occupational status (whether in paid employment or voluntary)

UNAIDS, 2008

- Financial hardship
- workload
- secrecy and fear of disclosure among people living with HIV
- Emotional involvement with people living with HIV and their families
- personal identification with the suffering of people with HIV
- awareness of unmet needs of clients' children
- Lack of effective voice in decisions affecting them and their work
- Inadequate support, supervision and recognition
- Inadequate training, skills and preparation for the work
- Lack of clarity over role/ expectations
- Lack of referral mechanisms
- Lack of medication and health care materials

Benefits of volunteering:

Crook et al., 2006

- Constructive feedback, recognition/ appreciation
- opportunity to participate in decision making, equity
- individual growth and development support
- social/ building/ sustaining events
- positive relationships
- sense of connectedness
- network of caring/ support
- improved skills and abilities
- improved employability

Richter et al., 1999

- Feelings of making a difference in people's lives
- Appreciation from clients and community
- Intellectual challenge and stimulation

APPENDIX 3: INFORMED CONSENT (ENGLISH VERSION)



Associations between personal attributes and compassion fatigue, compassion satisfaction and burnout among caregivers of people living with HIV and AIDS

Hello and welcome

Purposes of this research:

This study is looking at the effects that caring for people with HIV and AIDS has on you, the people who work with them. We know that this work can be very difficult and demanding on you personally, and that there are also positive rewards at times. This research is aimed at finding out more about how this work makes you feel, and what affects your ability to cope with the challenges.

Procedure: To gather information, the researcher will ask you to fill in some questionnaires. Each form has a unique number, but you will not be asked to write your name on them. There will be no way that the researcher or anybody else will be able to identify which are the ones you filled in. When you have filled them in, you are asked to put them in the sealed collection boxes. The information will later be analyzed by the researcher. All forms will be kept for five years in a safe place where only the researcher will have access to them. After this time they will be destroyed.

Sample: There will be 75 people participating in this research. They are all involved in caring for people with HIV and AIDS.

Confidentiality: Your identities will be protected; as there is no need for you to write your name on the questionnaires, nobody will know who filled them in. The signed consent forms will be kept separately from the questionnaires in a secure place where only the researcher will have access to them.

Potential risks and benefits:

- The research may take up 1-1½ hours of your time.
- Remember that if you feel stressed or upset at any time, you can take a break or even withdraw from the study. Additionally, the researcher can refer you to a counsellor if you would like to talk more.
- You may find it enjoyable and/or beneficial to have the chance to reflect on your work as a caregiver and how it affects you.
- We hope that what we find out from this study will be able to help you and other care workers in the future, by showing which things put you at risk of becoming exhausted, and which can make you feel stronger and better able to cope with the challenges.

All participants have the right to choose not to answer any question they do not wish to, or to withdraw from the study at any time.

Incentives: No money is offered for your participation. However, refreshments will be provided when you fill in your forms.

Contact details: If you have any further queries or comments about this research or your rights as a participant, please contact Trish Graaf (the researcher) on 033 342 9359 or 072 257 2316. Or you may contact the research supervisor, Professor J. D. Thwala, at the Psychology Department, University of Zululand on 035 902 6602/ 6610.

After reading this form, please feel free to ask the researcher any questions you may have about participating in this research. When you feel that you understand what participating will mean to you, you can decide whether or not you wish to enrol in this study.

Thank you for your help!

Your participation in this research is on a voluntary basis.





Authorisation:

I understand that my participation in this research is voluntary. I have read this form and the participant information sheet. My signature on this form indicates that I understand the information given on these documents.

I further acknowledge that the researcher _____ has informed me of the purposes, procedures, possible benefits, inconveniences and risks, and that I have had the opportunity to clarify these with her.

I have decided that I, _____ agree to participate in the study as it has been described.

I am aware that I am entitled to withdraw my consent at any time during the study without negative consequences.

My signature indicates that I have received a copy of this consent form.

Signature:

Date:

APPENDIX 3 (CONTINUED): INFORMED CONSENT (ZULU VERSION)



Associations between personal attributes and compassion fatigue, compassion satisfaction and burnout among caregivers of people living with HIV and AIDS

Sawubona futhi siyakwemukela

Purposes of this research:

Lolucwaningo lubheka imithelelsa yokunakelela abantu abanegciwane lengculazi enayo kuwe, nabantu osebenza ngabo. Siyazi ukuthi lomsebenzi ungaba nobunzima futhi ukukhahlameze, nokuthi kunezithelo ezinhle futhi kwezinye izikhathi. Lolucwaningo lubhekiswe ekuthenini luthole ulwazi olunzulu mayelana nokuthi lomsebenzi ukwenza ukuthi uzizwa kanjani, nokuthi yiziphi izinto ezinomthelela ekukwazini nokubhekana nezinqinamba.

Procedure: Ukuqoqa ulwazi, umcwaningi uzokucela ukuthi uphendule imibuzo efomini. Ifomu ngalinye linenombolo, kodwa awudingi ukuthi ubhale igama lakho kulona. Angeke kubekhona indlela yokuthi umcwaningi noma omunye umuntu angakwazi ukuthi yiliphi eligcwaliswe nguwe. Uma usuwagcwalisile, uyacelwa ukuthi uwafake ebhokisini elivalilwe, imininigwane iyocutshungulwa ngumcwaningi. Wonke amafomu ayogcinwa isikhathi esingangeminyaka emihlanu endaweni ephephile lapho koba umcwaningi kuphela oyokwazi ukufinyelela kuyo.

Sample: Kuzoba nabantu abangu-75 abazoba ingxenye yalolucwaningo. Bonke basebenza ngokunakekela abantu abanegciwane lengculazi.

Confidentiality: Awuzukudalalulwa; njengoba kungenasidingo sokuthi ubhale igama lakho efomini, akekho ozokwazi ukuthi ubani owagcalisile.

Amafomu ane-signature yakho onika kuwo imvume ayogcinwa endaweni ehluke kunale enamafomu ophendula khona imibuzo endaweni ephephile lapho kuyoba umcwaningi kuphela oyokwazi ukufinyelela kuyo.

Potential risks and benefits:

- Ucwangingo lungathatha isikhathi esiphakathi 1-1½ amahora esikhathi sakho.
- Khumbula ukuthi uma uzizwa uphatheka kabi noma u-streseka, ungathatha ikhefu noma ungavela ungaqhubeki nokuba ingxeny yocwangingo. Ngaphezu kwalokho, umcwaningi angakuthumela ekhanseleni uma ufisa ukukhuluma ngalokhu okukuphatha kabi.
- Ungathola ukuthi ungakujabulalela futhi/noma uthole ithuba lokubhekisisa umsebenzi wakho njengonompilo nokuthi ngabe unamthelela muni kuwe.
- Ngithemba ukuthi esikutholayo kulolucwangingo kungakwazi ukuthi kukusize nabanye abasebenzi esikhathini esizayo, ngokukhombisa ukuthi yiziphi izinto ezikubeka engcupheni yokuthi zikukhathaze, nokuthi yiziphi ezingakunika umdlandla/isibindi.

Bonke abayingxeny yalolucwangingo banelungelo lokukhetha ukuthi bangaphenduli umbuzo abangathandi ukuwuphendula, noma bayeke ukuba yinxeny lalolucwangingo noma yingasiphi isikhathi.

Incentives: Ayikho imali ozoyithola ngokuthi ube yinxeny yalolucwangingo. Kodwa ke, kuzoba khona okokusula umlomo/okuya ethunjini uma ugcwalisa amafomu.

Contact details: Uma uneminye imibuzo noma kukhona ofisa ukukusho mayelana nocwangingo noma mayelana namalungelo akho njengomuntu obambe iqhaza kulolucwangingo ucelwa ukuthi uthintane no-Trish Graaf (umcwaningi) ku- 033 342 9359 nom Profesa J.D. Thwala, eMkhakheni we-Psychology, University of Zululand ku-035 902 6602/6610.

Uma usuqedile ukufunda lelifomu, uyacelwa ukuthi ukhululeke ukuthi ubuze umcwaningi noma yimiphi imibuzo ongaba nayo ngokuba yingxenye yalolucwaningo. Uma uzizwa sengathi uyazi/uyaqonda ukuthi ukuba yingxenye yalolucwaningo kuchaza ukuthini kuwena, ungathatha isinqumo sokuthi uyafuna noma awufuni ukuba ingxenye yocwaningo.

Siyabonga ngosizo lakho!

Uyavolontiya ukuthi ubeyingxenye yalolucwaningo.



Ukunika imvume:

Nginyaqonda ukuthi ukuba yingxenye yalolucwaningo angizukhokhela ngiyavolontiya. Ngilifundile lelifomu naleli nolwazi mayelana nokuba yingxenye yalolucwaningo. I-signature yami kulelifomu lichaza ukuthi nginyaqonda ukuthi imininingwane/ulwazi enikezwe lona kulelibhuku.

Futhi ngiqonda ukuthi umcwaningi _____ ungangizisile ngezidingo, inqubo, engingakuthola, okungangikhinyabeza nobungozi, nokuthi ngibenalo ithuba lokuthi ngithole sicaciselane lezizinto naye.

Ngithathe isinqumo sokuthi mina, _____ ngiyavuma ukuba yingxenye yalolucwaningo ngengoba kuchaziwe.

Ngiyazi ukuthi nginelungelo lokuthi ngiyeke ukuba yingxenye yalolucwaningo noma yinini phakathi nocwaningo ngaphandle ukuthi kube namachaphazelo amabi.

I-signature yami ichaza ukuthi ngilitholile ikhophi lalelifomu lokunikeza imvume.

Signature:

Usuku:

APPENDIX 4: QUESTIONNAIRES (ENGLISH VERSION)

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 caregiver. Consider each of the following questions about you and your current working 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 with HIV and AIDS.
	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 caregiver.
	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 work as a caregiver.

	11. Because of my work as a caregiver, I have felt "on edge" about various things.
	12. I like my work as a caregiver.
	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 techniques and protocols for caring for people living with HIV and AIDS.
	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 caregiver.
	20. I have happy thoughts and feelings about those I help and how I could help them.
	21. I feel overwhelmed because my 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 the frightening experiences of the people I help.
	24. I am proud of what I can do to help people living with HIV and AIDS.
	25. As a result of my work as a caregiver, I have intrusive, frightening thoughts.
	26. I feel "bogged down" by the system.
	27. I have thoughts that I am a "success" as a caregiver.
	28. I can't recall important parts of my work with people with HIV and AIDS.
	29. I am a very caring person.
	30. I am happy that I chose to do this work.

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About you

Gender: ☐ Male
 ☐ Female

Age:

Current marital status:

☐ Married ☐ In a long term relationship

☐ Widowed ☐ Single/ never married

☐ Divorced ☐ Separated

Highest standard/ grade completed:

.....

Highest after school qualification:

.....

Occupational status:

☐ Currently employed ☐ Self employed

☐ Student ☐ Voluntary worker

☐ Retired ☐ Other (please specify)

Have you (or somebody you are close to) been directly affected by HIV or AIDS?

☐ Yes ☐ No

About your work as a caregiver:

How long have you been doing this work?

Are you currently: ☐ Paid to do this work

☐ Receiving a stipend ☐ Not receiving any remuneration

Approximate number of clients you see per week:

How long was the training you had to do this work?

.....

Do you feel that your training prepared you adequately for the work you are now doing as a caregiver?

- ☐ Yes, it was enough.
- ☐ Partly, but I feel that I need to learn more.
- ☐ No, it did not prepare enough me for the work I do with clients.

Do you have access to ongoing training or opportunities to develop your skills?

- ☐ Yes
- ☐ No

Do you have access to a counsellor or therapist if you are feeling distressed?

- ☐ Yes
- ☐ No

Do you ever feel that you and your clients are similar?

- ☐ Yes, I can understand them because I have a lot in common with them.
- ☐ Yes, there are some similarities, but also many differences.
- ☐ No, I do not have much in common with my clients.

Are you ever confused about which responsibilities are part of your job as a caregiver and which are not?

- ☐ Yes, I frequently feel unsure.
- ☐ Yes, sometimes I feel it is unclear.
- ☐ No, I am aware exactly what the limits of my job are.

Do you feel satisfied that you are doing your work well?

- ☐ Yes, overall I think I am doing a good job.
- ☐ Not sure.
- ☐ No, I am not doing enough.

If clients need help with things that are not part of your work as a carer, are you able to refer them to somebody who can assist them?

- ☐ Yes, I am satisfied that I know where to send people to access help.
- ☐ Sometimes, but in other cases I don't know how they can access help.
- ☐ No, there is no other assistance for the people I work with.

Do you feel that you are stigmatised by other people because of your work with people who have HIV or AIDS?

- ☐ Yes, I experience a lot of stigmatisation because of my work.
- ☐ Yes, I am sometimes exposed to stigmatisation because of my work.
- ☐ No, I have not been stigmatised as a result of my work.

Do people in your life (for example friends or family) give you support and encouragement?

- ☐ Yes, I am strengthened by people I am close to.
- ☐ Sometimes.
- ☐ No, not usually.

Is there a person (or people) within your organisation who gives you help and advice relating to your work with clients?

- ☐ Yes
- ☐ No

How often do you do things that help you to relax and feel good?

- ☐ Regularly – caring for myself is important to me.
- ☐ Sometimes, if I have the time and energy.
- ☐ Seldom or not at all. Caring for others uses up all my time and energy.

APPENDIX 4 (CONTINUED): QUESTIONNAIRES (ZULU VERSIONS)

Professional Quality of Life Scale (ProQOL)

Compassion Satisfaction and Compassion Fatigue (ProQOL) Version 5 (2009)

Uma usiza abantu uthinta izimpilo zabo. Njengoba usubonile, ukuzwelana kwakho nalobo obasizayo kungathinta impilo yakho njendlela enhle futhi nangendlela engeyinhle. Ngezansi eminye yemibuzo emayelana nezimo ohlangabezana nazo, kungaba ezinhle noma ezimbi, njengonompilo. Ucelwa ukuthi ubheke ngamunye walemibuzo mayelana nawe nomsebenzi owenza njengamanje. Khetha inombolo okuyiyona eshaya esikhonkosini ukuthi uhlangane kaningi kangakanani nalezizimo kulezizinsuku eziwu-30 ezedlule.

1 = Akwenzeki

2 = Akuvamile

3 = Njezinye izikhathi

4 = Kaningi

5 = Kuhlale kwenzeka

	1. Ngijabulile.
	2. Ngiyaxakeka ngabantu abangaphezu koyedwa engibasizayo.
	3. Ngithola ukwaneliseka ekusizeni abantu aba negciwane lesandlulela ngculazi nengculazi uqobo.
	4. Ngizizwa ngixhumene nabanye abantu.
	5. Ngiyathuswa imisindo ebengingayilindele.
	6. Ngizizwa ngivuseleleka ngemva kokusebenza nalabo bantu.
	7. Ngibhekana nobunzima ekuhlukaniseni impilo yami nempilo yokuba ngumnakekeli.
	8. Angikwazi ukwenza umsebenzi wami kahle/ngokuphelele ngoba angitholi ukulala kahle/ngiqwashiswa/ngiphatheke kabi ngenxa yezinto ezithusayo/ezibuhlungu, ezenzeka kumuntu engimsizayo.
	9. Ngicabanga ukuthi kungenzeka ukuthi ngiphathwa kabi izinto ezibuhlungu ezenzeka kulaba engibasizayo.
	10. Ngizizwa sengathi ngibophekile/ngibambekile ngenxa yomsebenzi wami njengonompilo.

	11. Ngenxa yomsebenzi wami njengonompilo, ngiyaye ngizizwe ngingakhululekile/ngikhathazekile ngezinto eziningi.
	12. Ngiyawuthanda umsebenzi wami njengonompilo.
	13. Ngizizwa ngiphansi/ngiphatheke kabi ngenxa yezinto ezibuhlungu ezenzika kulabo engibasizayo.
	14. Ngizizwa sengathi yithatha ubuhlungu balomuntu engimsizayo.
	15. Nginezinkholelo ezingisizayo ukuba ngiqhubeke.
	16. Kuyangijabulisa ukuthi nginethuba lokuthi ngihlale ngithola ulwazi olusha nezindlela ezintsha zokunakekela abantu abanegciwane lengculazi.
	17. Ngiyilomuntu engangihlale ngifisa ukuba nguwe.
	18. Umsebenzi wami ungenza ukuba ngibe nokwaneliseka.
	19. Ngizizwa ngikhandlekile ngenxa yomsebenzi wami wokuba unompilo.
	20. Nginemizwa nemicabango yokujabula uma ngicabanga ngalabo engibasizayo nokuthi ngigabasiza kanjani.
	21. Ngizizwa sengathi umsebenzi wami njengonompilo mningi ngoba ngihlale ngisebenzi awupheli.
	22. Ngikholwa ukuthi ngingenza umehluko ngomsebenzi wami.
	23. Ngiyazigwema izinto ezithihle noma imisebenzi ethile ngoba ingikhumbuza izimo ezibuhlungu zabantu engibasizayo.
	24. Ngiyaziqhenya ngalokho engikwenzayo ukusiza abantu abachaphazelekile isandulela ngculazi nengculazi uqobo.
	25. Ngenxa yomsebenzi wami njengonompilo, ngiba nemicabango ethusayo.
	26. Ngizizwa sengathi uhulumeni akasisizi kodwa ngathi wenza umsebenzi wethu ubenzima.
	27. Nginemicabango ukuthi “ngiyimpumelelo” njengonompilo.
	28. Angisazikhumbuli izingxenywe ezibalulekile zomsebenzi wami nabantu abachaphazelwe isandulela ngculazi nengculazi uqobo.
	29. Ngingumuntu onozwelo/onakekelayo.
	30. Ngithokozile ngokuthi ngakhetha lomsebenzi.

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Mayelana nawe

Ubulili: ☐ Isilisa
 ☐ Isifazane

Iminyaka:

Mayelana nobudlelwane:

<input type="checkbox"/> Ushadile	<input type="checkbox"/> Usebudlelwaneni obunesikhathi eside
<input type="checkbox"/> Washonelwa	<input type="checkbox"/> Awukaze ushade
<input type="checkbox"/> Udivosile	<input type="checkbox"/> Nehlukanisile

Izinga lesikole owagcina kulo:

Wafundela ini emva kwe High school:

.....

Ngokomsebenzi:

<input type="checkbox"/> Uyasebenza njengamanje	<input type="checkbox"/> Uyazisebenza
<input type="checkbox"/> Umfundi	<input type="checkbox"/> Uyivolontiya
<input type="checkbox"/> wathatha umhlalaphansi	<input type="checkbox"/> Okunye (chaza)

Kungabe wena (noma osondelene nawe) uphethwe isifiso sengculazi (HIV noma AIDS)?

<input type="checkbox"/> Yebo	<input type="checkbox"/> Chabo
-------------------------------	--------------------------------

Umsebenzi wakho njenge-caregiver:

Kungabe sekuyisikhathi esingakana wenza lomsebenzi??

.....

Kungabe: ☐ Uyakhokhelwa/uyahola ukwenza lomsebenzi

☐ Uyayithola imali yokugibela

☐ awuyitholi lutho/awuholi

Inamba yabantu obabonayo ngesonto uma uhlawumbisela:

.....

Kwathatha isikhathi esingakanani ukufundela lomsebenzi?

.....

.....

Kungabe ucabanga ukuthi i-training owayithola ukuthi wenze lomsebenzi yanele ukuthi wenze kahle umsebenzi wakho?

☐ Yebo, yanele.

☐ Mbijana/kancane, kodwa ngicabanga ukuthi kukhona ekumele ngikufunde.

☐ Cha, ayinginikanga ukuqeqesheka okwanele ngomsebenzi engiwenzayo.

Kungabe uyaluthola yini ulwazi mayelana nezifundo ezingakunika usizo oluthe thuthu ukuze ukwazi ukusebenza kahle

☐ Yebo

☐ Chabo

Kungabe uyakwazi ukuthola usizo lwekhansela noma i-therapist uma uzizwa ungakhululekile noma ustresekile?

☐ Yebo

☐ Chabo

Kungabe kuyenzeka ukuthi uzizwe sengathi wena nabantu obasizayo niyafana?

- ☐ Yebo, ngiyakwazi ukuzwelana nabo ngoba siphila izimpilo ezifanayo.
- ☐ Yebo, zikhona izinto ezifanayo kodwa futhi kuningi okuhlukile ezimpilweni zethu.
- ☐ Chabo, azikho izinto engingathi ziyafana empilweni yami nabantu engisebenza ngabo.

Kungabe kuyenzeka ukuthi ukudideke ukuthi yikuphi okungumsebenzi wakho njenge-caregiver okumele ukwenze nokungamele ukukwenze?

- ☐ Yebo, kujwayelekile ukuthi ngidideke/ngingabinasiqiniseko.
- ☐ Yebo, kuyenzeka ukuthi ngingabinasiqiniseko.
- ☐ Cha, ngazi kahle ukuthi umsebenzi wami ugcina wakho.

Kungabe wenelisekile ngokuthi wenza umsebenzi oncomekayo?

- ☐ Yebo, ngicabanga ukuthi ngenza umsebenzi oncomekayo.
- ☐ Anginasiqiniseko.
- ☐ Chabo, angenzi okwanele.

Uma abantu obasizayo bedinga usizo mayelana nento engasiwona umsebenzi njengosonhlalakahle, kungabe uyakwazi ukuthi ubayalele umuntu ongakwazi ukubasiza?

- ☐ Yebo, nganelisekile ngokuthi ngiyazi ukuthi abantu ngingabayela ukuthi baye kuphi ukuze bathola ulwazi.
- ☐ Ngezinye izikhathi, kodwa kuyenzeka ukuthi ngingazi ukuthi bangalutholaphi ulwazi.
- ☐ Chabo, akukho okunye ukusizakala kwabantu engisebenza nabo.

Kungabe uzizwa engathi uyacwaseka kwabanye abantu ngenxa yokusebenza nabantu abanegciwane lengculazi (HIV noma AIDS)?

- ☐ Yebo, ngiyacwaseka ngenxa yomsebenzi engiwenzayo.
- ☐ Yebo, kuyenzeka kwezinye izikhathi ukuthi ngithole ukucwaseka ngenxa yomsebenzi wami.
- ☐ Chabo, angikaze ngicwaseka ngenxa yomsebenzi engiwenzayo.

Kungabe abantu abasempilweni yakho (isibonelo abangani noma umndeni) bayakugqugquzela bakunike nesaphothi?

- ☐ Yebo, abantu abasondelene nami.
- ☐ Kwezinye izikhathi.
- ☐ Chabo, akwenzeki njalo.

Kungabe kukhona umuntu (noma abantu) enhlanganweni yenu okunikeze usizo nezeluleko mayelana nomsebenzi owenzayo?

- ☐ Yebo
- ☐ Chabo

Kuvamise kangakanani ukuthi wenze izinto ezikwenza u-relax noma ukhululeke?

- ☐ Njalo – ukuzinakekela kubalulekile kimi.
- ☐ Kuyenzeka kwezenye izikhathi, uma nginesikhathi nomdlandla.
- ☐ Kuyathukela nje noma akwenzeki. Ukunakekela abanye abantu kuthatha sonke isikhathi nomdlandla wami.

APPENDIX 5: GROUP STATISTICS

Gender

Variable	Gender	Mean	Standard deviation
Compassion Satisfaction	Male (N=11)	52	8.14
	Female (N=69)	58.3	8.64
Burnout	Male (N=11)	56.4	5.77
	Female (N=65)	49.5	9.75
Secondary Traumatic Stress	Male (N=10)	71.8	4.56
	Female (N=67)	69.2	8.96

Current marital status

Variable	Marital status	Mean	Standard deviation
Compassion Satisfaction	Single (N=52)	58.9	8.17
	With partner (N=27)	54.6	9.55
Burnout	Single (N=51)	50.1	8.55
	With partner (N=25)	51.4	11.5
Secondary Traumatic Stress	Single (N=49)	68.1	7.96
	With partner (N=27)	72.1	9.23

Scholastic education

Variable	Education level	Mean	Standard deviation
Compassion Satisfaction	None (N=6)	55.2	5.47
	Certificate (N=53)	57.2	9.64
	Diploma (N=9)	57.7	6.63
	Degree (N=1)	45.7	-
Burnout	None (N=6)	48.2	5.12
	Certificate (N=51)	49.9	10.56
	Diploma (N=9)	53.4	6.27
	Degree (N=1)	56	-

Secondary Traumatic Stress	None (N=4)	73.4	7.37
	Certificate (N=51)	68.1	8.70
	Diploma (N=9)	70.63	4.76
	Degree (N=1)	65.9	-

Post-school education

Variable	Education level	Mean	Standard deviation
Compassion Satisfaction			
Burnout			
Secondary Traumatic Stress			

Occupational status

Variable	Occupational status	Mean	Standard deviation
Compassion Satisfaction	Unemployed (N=5)	59.1	3.86
	Volunteer (N=40)	55.1	8.87
	Student (N=4)	65.4	5.51
	Retired (N=1)	68.6	-
	Employed (N=31)	58.3	9.18
Burnout	Unemployed (N=5)	55.2	6.301
	Volunteer (N=38)	51.7	10.24
	Student (N=4)	42.8	5.919
	Retired (N=1)	60	-
	Employed (N=29)	49.2	8.99
Secondary Traumatic Stress	Unemployed (N=5)	73.5	6.68
	Volunteer (N=39)	70.63	9.13
	Student (N=4)	68.3	2.05
	Retired (N=1)	75.4	-
	Employed (N=29)	67.6	8.44

Personal history

Variable	Personal history	Mean	Standard deviation
Compassion Satisfaction	No (N=33)	56.2	10.17
	Yes (N=45)	58.3	7.76
Burnout	No (N=33)	50.88	9.74
	Yes (N=42)	50.17	9.65
Secondary Traumatic Stress	No (N=31)	67.2	7.21
	Yes (N=44)	71.4	8.84

Remuneration

Variable	Remuneration	Mean	Standard deviation
Compassion Satisfaction	None (N=12)	56.07	11.6
	Stipend (N=31)	54.8	9.298
	Paid (N=36)	58.7	8.65
Burnout	None (N=12)	54.4	7.29
	Stipend (N=32)	50.56	11.3
	Paid (N=31)	5.32	8.608
Secondary Traumatic Stress	None (N=11)	75.1	6.95
	Stipend (N=31)	69.7	8.89
	Paid (N=35)	69.05	8.77

Perceived adequacy of training

Variable	Training adequacy	Mean	SD
Compassion Satisfaction	Inadequate (N=5)	57.1	8.081
	Partly adequate (N=40)	56.07	9.045
	Sufficient (N=36)	57.5	9.97
Burnout	Inadequate (N=5)	53.2	3.27
	Partly adequate (N=35)	50.66	10.38
	Sufficient (N=37)	50.3	9.53

Secondary Traumatic Stress	Inadequate (N=4)	76.6	7.82
	Partly adequate (N=38)	70.97	9.13
	Sufficient (N=36)	67.9	8.19

Access to ongoing training

Dependent variable	Ongoing training	Mean	SD
Compassion Satisfaction	No (N=13)	55.6	8.80
	Yes (N=69)	57.2	9.51
Burnout	No (N=11)	54.9	6.7
	Yes (N=67)	50.09	9.87
Secondary Traumatic Stress	No (N=12)	74.3	7.87
	Yes (N=67)	69.1	8.75

Access to counselling and therapy

Dependent variable	Counselling/ therapy	Mean	SD
Compassion Satisfaction	No access (N=37)	54.9	10.53
	Yes (N=44)	58.5	8.13
Burnout	No (N=35)	52.4	10.3
	Yes (N=42)	49.3	8.97
Secondary Traumatic Stress	No (N=34)	73.4	8.96
	Yes (N=44)	66.9	7.39

Identification with clients

Dependent variable	Identification	Mean	SD
Compassion Satisfaction	No (N=7)	54.08	8.98
	In part (N=45)	58	9.29
	Yes (N=29)	55.8	9.72
Burnout	No (N=6)	58	9.32
	In part (N=44)	50.41	8.58
	Yes (N=28)	49.8	10.809

Secondary Traumatic Stress	No (N=5)	73.2	4.84
	In part (N=44)	69.6	7.86
	Yes (N=29)	70.42	10.205

Role clarity

Dependent variable	Clarity	Mean	SD
Compassion Satisfaction	Frequently unsure (N=13)	49.01	9.63
	Some uncertainty (N=28)	55.3	9.58
	Certain (N=41)	60.59	7.207
Burnout	Frequently unsure (N=13)	58.08	7.57
	Some uncertainty (N=28)	52.4	10.13
	Certain (N=37)	47	8.06
Secondary Traumatic Stress	Frequently unsure (N=13)	72	6.57
	Some uncertainty (N=26)	74.6	7.49
	Certain (N=40)	66.2	8.63

Perceived efficacy

Dependent variable	Effective	Mean	SD
Compassion Satisfaction	No (N=4)	52.5	4.27
	Unsure (N=12)	51.6	11
	Yes (N=66)	58.2	8.94
Burnout	No (N=4)	51.3	23.9
	Unsure (N=12)	55.8	7.056
	Yes (N=62)	49.8	8.56
Secondary Traumatic Stress	No (N=4)	75.8	12.5
	Unsure (N=11)	75.1	6.61
	Yes (N=64)	68.6	8.51

Referral mechanisms

Dependent variable	Referral mechanisms	Mean	SD
Compassion Satisfaction	No (N=1)	58.6	-
	Sometimes (N=8)	54.3	7.32
	Yes (N=73)	56.9	9.63
Burnout	No (N=1)	63	-
	Sometimes (N=9)	52.3	14.3
	Yes (N=68)	50.38	8.88
Secondary Traumatic Stress	No (N=1)	69.05	-
	Sometimes (N=9)	73.1	9.88
	Yes (N=69)	69.5	8.69

Perceived stigma

Dependent variable	Stigma	Mean	SD
Compassion Satisfaction	No (N=29)	59.9	8.44
	Sometimes (N=31)	53.9	10.4
	A lot (N=19)	57.1	8.42
Burnout	No (N=28)	46.2	7.87
	Sometimes (N=30)	53.2	10.67
	A lot (N=18)	54.8	7.22
Secondary Traumatic Stress	No (N=27)	66	8.72
	Sometimes (N=31)	72.02	8.48
	A lot (N=18)	73.5	6.64

Social support

Dependent variable	Support	Mean	SD
Compassion Satisfaction	No (N=3)	43.8	18.09
	Sometimes (N=21)	53.9	8.93
	Yes (N=56)	59.1	8.13

Burnout	No (N=3)	61.7	9.07
	Sometimes (N=21)	53.3	11.006
	Yes (N=52)	49	8.59
Secondary Traumatic Stress	No (N=3)	83.9	5.57
	Sometimes (N=20)	73.2	7.13
	Yes (N=54)	67.7	8.53

Organisational support

Dependent variable	Support	Mean	SD
Compassion Satisfaction	No (N=6)	52.9	14.8
	Yes (N=74)	57.5	8.89
Burnout	No (N=6)	46.8	18.9
	Yes (N=70)	51.01	8.62
Secondary Traumatic Stress	No (N=6)	79.1	10.51
	Yes (N=71)	69.07	8.37

Self care

Dependent variable	Self-care	Mean	SD
Compassion Satisfaction	Seldom/ never (N=4)	49.3	13.2
	Sometimes (N=34)	57.6	9.64
	Regular (N=42)	57.5	8.74
Burnout	Seldom/ never (N=4)	47	22.2
	Sometimes (N=32)	50.91	8.33
	Regular (N=40)	50.9	9.23
Secondary Traumatic Stress	Seldom/ never (N=4)	80.56	12.5
	Sometimes (N=32)	70.34	8.34
	Regular (N=41)	68.4	8.43

APPENDIX 6: CORRELATION MATRIX

Correlations									
	CS T-score	Burnout T-score	STS T-score	Highest grade in school	Experience in months	Caseload estimate per week	Caregiver training in weeks	Age	
CS T-score	1	-.586**	-.418**	-.117	-.068	.072	-.136	.154	
Pearson Correlation		.000	.000	.309	.560	.523	.248	.184	
Sig. (2-tailed)									
N	82	77	78	78	75	80	74	76	
Burnout T-score	-.586**	1	.456**	-.133	-.069	-.015	.225	.017	
Pearson Correlation		.000	.000	.256	.570	.895	.060	.889	
Sig. (2-tailed)									
N	77	78	74	75	71	76	71	73	
STS T-score	-.418**	.456**	1	-.225	.167	.056	.106	.070	
Pearson Correlation		.000	.000	.052	.161	.630	.377	.559	
Sig. (2-tailed)									
N	78	74	79	75	72	77	71	73	
Highest grade in school	-.117	-.133	-.225	1	.059	.031	.123	-.447**	
Pearson Correlation		.309	.052		.623	.790	.306	.000	
Sig. (2-tailed)									
N	78	75	75	79	73	77	71	75	
Experience in months	-.068	-.069	.167	.059	1	.412**	.407**	.295*	
Pearson Correlation		.560	.161	.623		.000	.001	.012	
Sig. (2-tailed)									
N	75	71	72	73	76	74	69	71	
Caseload estimate per week	.072	-.015	.056	.031	.412**	1	.091	.111	
Pearson Correlation		.523	.630	.790	.000		.442	.345	
Sig. (2-tailed)									
N	80	76	77	77	74	81	73	75	
Caregiver training in weeks	-.136	.225	.106	.123	.407**	.091	1	.011	
Pearson Correlation		.248	.377	.306	.001	.442		.927	
Sig. (2-tailed)									
N	74	71	71	71	69	73	75	69	
Age	.154	.017	.070	-.447**	.295*	.111	.011	1	
Pearson Correlation		.184	.559	.000	.012	.345	.927		
Sig. (2-tailed)									
N	76	73	73	75	71	75	69	77	

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).