Coping Strategies of Community Health Workers Providing Home-Based Care for HIV/AIDS: A Comparison of High & Low Burnout Groups

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DECLARATION

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This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signed by candidate

Kirtesh Mohan Dullabh

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ABSTRACT

This study aims to explore the coping resources that community health workers (CHWs), providing home-based care to people with AIDS (PWAs), draw on in response to stressful work experiences. Furthermore, the study explores whether different coping mechanisms are utilised by health care workers at different points on the burnout continuum. CHWs were selected from a community outreach organisation in Cape Town. A Xhosa version of the Maslach Burnout Inventory (MBI) was administered to forty-five CHWs. From this group, twelve participants were selected for in-depth interviews, six from both the higher and lower ends of the burnout continuum. Thematic analysis of the interviews indicate that both the High and Low Burnout groups confront similar stressors as a result of going beyond the call of duty, community and familial stigmatisation and working in adverse conditions. In addition, CHWs from both groups have difficulty articulating their emotional needs. The groups differed on the number of HIV/AIDS caseloads, with the High Burnout group treating more PWAs than the Low EE group. Carers also differ in their coping styles: High Burnout participants rely more on emotion-focussed coping, denial and escape avoidance, and appear to have a limited repertoire of coping skills, while Low Burnout participants are more predisposed to using problem-focussed coping with the flexible inclusion of emotion-focused approaches. The study also highlights how the context of care affects coping. Limitations of the present study are discussed, and recommendations made for future research and practice in the field.

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CHAPTER ONE

INTRODUCTION

South Africa has one of the most rapidly growing HIV/AIDS epidemics in the world. Between 1990 and 1998 the HIV prevalence in women alone increased from 0.73 % to 22.8%, and from 1.6 % to 32.5% in KwaZulu-Natal, the province with the highest prevalence rates in the country (Department of National Health, 1999 cited in Michele & Schneider, 2000). In 1998, an estimated 50 per cent of all new infections in sub-Saharan Africa occurred in South Africa (Uys, 2001). A conservative estimate is that by the year 2005 there will be nearly 1 million AIDS orphans in the country (Abdool Karim et al., 1997 cited in Michele & Schneider, 2000), doubling to 2 million by 2010 (Desmond, Gow, Loening-Voysey, Wilson and Stirling, 2002).

The current rate of HIV/AIDS infection places an inconceivable strain on an already under-resourced health care system; consequently much of the burden falls onto households and communities (Michele and Schneider, 2000). Michele and Schneider (2000, p. 2) state that, "Any discussion of AIDS care and support turns to a consideration of how to achieve greater community participation, both in minimizing impacts on the formal health sector and in meeting the needs of people infected and affected by HIV." In an attempt to address this need, home-based care has been identified by the National AIDS Convention of South Africa as an important element of the national AIDS strategy to reduce the personal and social impact of HIV (Nacosa, 1994 cited in Soal, 1997).

Home-based care for HIV/AIDS had been introduced in most African countries during the late 1980s and early 1990s (Sims & Moss, 1995 cited in Uys, 2002). However, concern has been expressed regarding the practice of home based care in Africa due to the crowded and substandard conditions in which most people with AIDS (PWAs) live (Spier & Edwards, 1990 cited in Uys, 2002). Home-based care in an impoverished setting poses a host of challenges to the caregiver. In focusing on their clients needs, there are times when the needs of the caregivers have been neglected both by themselves and the by the system in which they function. This bias is replicated in the research literature, which focuses on needs of PWAs rather than its carers (Bennett, Kelaher & Ross, 1994). Under the chronic pressure to meet the needs of an overwhelming number of PWAs, caregiver's own mental and physical health are negatively affected, often leading to burnout in the long term. Burnout is described as an extreme expression of work stress – the end stage of a chronic process of deterioration and frustration in the individual worker (Miller, 2000). Coping strategies act as significant predictors and mediators of burnout (Carver, Weintraub & Scheier, 1989; Duquette, Sandhu & Baeudet, 1994; Etzion & Pines, 1986; Jansen, Kerkstra, Abu-Saad & Van de Zee, 1996; Kilfedder, Power & Wells, 2001; Payne, 2001; Thornton, 1991). It is therefore crucial to gain insight into the relationship between coping and its mitigating influence on the experience of burnout (Florence, 1998).

The majority of research into the impact of care giving on caregivers has been derived from samples of nurses, social workers, doctors, teachers and police, with relatively little research into community health workers providing home based care (Horsman & Sheeran, 1995), which in the South African context is a major proportion of the care required. The specific focus of this paper will be on the experience of community health workers (CHW) providing home-based care for PWAs in Cape Town.

1.1. Rationale and Aims

Given the high rates of infection and extensive constraints on the health care system, CHWs in the South African context are at high risk of burnout. There are a multitude of consequences to burnout, the most significant being a high turnover rate, which ultimately undermines HIV/AIDS care (Medical Letter on the CDC & FDA, 2002). The bulk of the research on coping and burnout, which has been carried out in the context of Western health care, has neglected the experience of CHWs providing home-based care (Horsman & Sheeran, 1995). Given the movement towards providing home-based care in South Africa, it is crucial to identify the needs of CHWs, who form a vital part of the care-giving nexus, so as to minimize burnout.

In the last decade, considerable attention has been placed on care for caregivers, however in order to provide such care it is important to listen to caregivers' experiences, understand the resources they draw on, and identify those they lack or require. Once researchers have gained more insight into caregivers experiences, interventions aimed at minimizing burnout can be implemented.

The aims of the study are to qualitatively explore the experience of CHWs working with PWAs, to explore coping strategies they use, and particularly to explore whether CHWs who are at risk of burnout use different coping strategies than those who are not at risk.

1.2. Overview of Chapters

The remainder of this thesis is detailed in five chapters. Chapter Two presents a theoretical framework and understanding of the concepts of coping and burnout. Definitions and dimensions of coping identified in the literature are reviewed. An overview of the existing literature in relation to burnout and its mediating factors is provided, followed by an exploration of the relationship between coping and burnout. Research on burnout in the context of HIV/AIDS, and existing research on burnout in the South African context will be reviewed, followed by an overview of the limitations of previous research on burnout and coping, and their implications for the study of HIV/AIDS caregivers.

Chapter Three provides an overview of the methodology employed in collecting and analysing data. A detailed description of the overall research design is provided, followed by a discussion of the research instruments utilised. The use of a translator in cross-cultural research is also addressed. The chapter concludes with an overview of the method of data analysis, and a discussion of ethical considerations in the present study.

Chapter Four presents and interprets the findings. Participant scores on the Maslach Burnout Inventory are considered, followed by a thematic analysis of the interview data, which draws out both similarities and differences between the high and low burnout groups. Finally Chapter Five draws conclusions from the present study, acknowledging limitations, and making recommendations for future research.

CHAPTER TWO

LITERATURE REVIEW

2. Introduction to Chapter

This chapter aims to review and theoretically discuss the concept of coping in relation to burnout. The literature on coping, burnout and mediating factors of burnout are explored, as well as the existing knowledge on coping strategies in relation to burnout. The available literature on burnout in relation to home-based care in South Africa will also be reviewed. The chapter concludes with the limitations of the research in the field, motivating for a more qualitative methodology in this area of research.

2.1. Coping

Lazarus and Folkman (1984, p. 141) define coping as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person." In addition, they assert that the definitions of coping must include any and all efforts to manage stressful demands irrespective of outcomes, with the implication that no one strategy is inherently better than the other. Lazarus (1966, cited in Carver et al., 1989) contexualised coping within the three processes in response to stress: Primary appraisal, characterised by perceiving a threat to oneself; secondary appraisal, being the process of eliciting a potential response to the threat; and finally coping, which is the process of executing that response.

Lazarus and Folkman (1984) draw a distinction between emotion-focused and problem-focussed coping. Emotion-focussed coping aims at reducing or managing the emotional distress associated with the situation and is usually adopted in response to stressors that need to be endured, as they cannot be changed (Lazarus & Folkman, 1980, cited in Carver et al., 1989). Emotion-focussed strategies include avoidance, minimization, distancing, selective attention, positive comparisons, and drawing positive values from negative events (Lazarus and Folkman, 1984). Lazarus and Folkman (1984) further identify a smaller group of cognitive strategies aimed at increasing emotional distress. Some individuals need to feel worse before feeling better, while in other situations individuals deliberately increase their emotional distress in order to mobilise themselves, which has been equated to the concept of *psyching oneself up*. Certain cognitive strategies of emotion-focused coping reappraise the situation without changing it objectively, while in other cases avoiding a situation changes its meaning depending on what is being avoided. Alternately the meaning of an encounter can remain the same even if some aspects are screened out (Lazarus & Folkman, 1984).

Problem-focussed coping is similar to problem solving; such efforts are directed at defining the problem, generating alternative solutions and weighing the alternatives in terms of costs and benefits with the ultimate aim of alleviating the stress (Lazarus & Folkman, 1984). Khan, Wolfe, Quinn, Snoek and Rosenthal (1964 cited in, Lazarus & Folkman, 1984) delineate two major problem-orientated strategies. The first is directed outward at the environment, aimed at altering environmental pressures, barriers, resources and procedures. The second strategy, directed inward, manifests as motivational and cognitive changes, such as shifting the level of aspiration, reducing ego-involvement, finding alternative channels of gratifications or developing new skills and/or behaviour.

Although stressors usually elicit both types of responses, it has been argued that problem-focussed coping is utilised in situations where the individual feels that something constructive can be done (Carver et al., 1989). Lazarus and Folkman (1984, p. 139) draw attention to the fact that "emphasising problem solving and mastery devalues other functions of coping that are concerned with managing emotions and maintaining self-esteem and a positive outlook, especially in the face of irremediable situations. Coping processes that are used to tolerate such difficulties, or to minimize, accept, or ignore them are just as important in the persons adaptation armamentarium as problem-solving strategies that aim to master the environment."

Lazarus and Folkman (1984) state that problem/emotion-focussed coping interact and influence each other throughout a stressful situation, either facilitating or impeding each other. The way a person copes is mediated by the resources available to the individual: "health and energy; existential beliefs, e.g., about God, or general beliefs about control; commitments, which have a motivational property that can help sustain coping; problem solving skills; coping skills; social support and material resources" (Lazarus & Folkman, 1984, p 179). Coping in response to a stressor is also determined by personal and environmental constraints that limit the full use of these of resources (Lazarus & Folkman, 1984).

The problem/emotion-focussed distinction has been the dominant manner in which researchers have conceptualised coping (Carver et al., 1989; Melnick, 2002; Ogus, 1992; Rose & Clark-Alexander, 1999). Carver et al. (1989) argue that while this distinction remains an important one, it has proven to be too simplistic. In general, researchers tend to view factors other than problem-focussed coping as variations of emotion-focussed coping. In this regard some emotion-focussed efforts thus involve such diverse strategies as denial, or seeking out social support. Additionally, Carver et al. (1989) argue that problem-focused coping requires closer scrutiny; although it appears to be a single process it potentially involves several distinct activities.

While maintaining the problem/emotion-focussed distinction, Carver et al. (1989) developed the COPE scale, which assesses a wider range of conceptually distinct aspects of problem/emotion-focused strategies that facilitate or impede effective coping. (See Table 1 on page 9)

Like Carver et al. (1989), Lazarus and Folkman (1984) make particular reference to denial as a coping strategy. In psychoanalytic theory, denial is conceptualised as an unconscious defence, described by Anna Freud as an attempt "to get rid of unwelcome facts" (Freud, 1936, cited in Mitchell & Black, 1995, p.30). Janis (1958, cited in Lazarus & Folkman, 1984) asserts that the individual employing denial, or even more conscious cognitive and emotional avoidance, as a way of coping will initially experience emotional ease, but that he/she remains vulnerable to stressors on subsequent occasions. By contrast the individual who confronts stressor/s at the outset may experience initial distress, but less so on subsequent occasions (Janis, 1958 cited in Lazarus & Folkman, 1984).

However denial can have either favourable or unfavourable outcomes. When nothing constructive can be done to alleviate a potential harm or threat, denial processes may lessen distress without altering functioning or leading to additional harm: "In chronically uncontrollable (unchangeable) situations, the strategy of choice may be one that effectively reduces both arousal and concomitant processing of information from the environment " (Miller, 1980, cited in Lazarus and Folkman, 1984, p.137). Denial may be adaptive in certain situations; in this regard denial of implication has been distinguished from denial of fact. Denial of fact or distorting reality is more harmful than denying the implications of such situations, which is more akin to illusion, positive thinking or hopefulness (Lazarus & Folkman, 1984).

Table 1: Dimensions of Coping

(Carver et al., 1989)

Coping Strategy	Description
Active Coping	A systematic approach aimed at actively alleviating the stressor and its subsequent effects. Active coping is synonymous with problem-focussed coping.
Planning	This involves thinking about how to better manage the stressor and the steps to follow in doing so. This usually occurs during secondary appraisal, while active coping takes place in the coping phase.
Suppression of competing activities	This involves prioritising by putting aside projects and letting go of certain responsibilities in order to focus exclusively on the stressor.
Restraint coping	Waiting for the appropriate moment to respond to the stressor. While it is an active coping strategy, as the individual is focussed on dealing with the stressor, it is simultaneously passive as restraint usually means not acting.
Social Support	Individuals can seek out social support for instrumental reasons, e.g. for advice, information or assistance. Social support may also be sought for emotional reasons. The former constitutes problem-focussed coping while the latter is more emotion-focussed; both aspects usually co-exist.
Focussing on and venting of emotions	This response can be considered functional if through expression of one's emotional distress one can move forward. However, this response may be maladaptive given the focus on one's distress (particularly over long periods), which may impede adjustment. Lazarus and Folkman (1984, cited in Anderson, 2000) state that high levels of emotion-focussed coping of this nature adversely affect cognitive functioning.
Behavioural Disengagement	This involves reducing one's efforts in dealing with the stressor, usually the case when people expect poor outcomes. A variation of this is **Mental Disengagement** in which the individual employs a variety of tactics to distract him/herself from the stressor. Arguably, disengagement from a stressor under certain conditions may be adaptive, however this response often impedes functioning.
Positive Reinterpretation And Growth	This has been regarded as a type of emotion-focussed coping aimed more at managing the emotional distress rather than the source of the stress.
Denial	Occasionally this response emerges in primary appraisal. Denial may be adaptive in certain contexts as it minimizes distress and facilitates coping. Alternately, denial of reality may allow the situation to be exacerbated, causing significantly more distress when eventual coping of the situation is required. Denial may be useful in the early stages of a stressful transaction but can impede coping later on. This has also been referred to as counterproductive palliation (Ogus, 1992).
Acceptance	This would imply that the person accepts the reality of the situation and is engaged in an attempt to deal with it.
Turning to Religion	A coping technique important to many. It may be a source of emotional support, positive reinterpretation or growth, or a tactic of active coping.

Aldwin and Revenson (1987, cited in Thornton, 1991) observed that the coping strategy of escape-avoidance (out of eight different problem and emotion-focussed strategies) was most frequently related to psychological symptoms. In a similar study, Billing and Moos (1981, cited in Thornton, 1991) concluded that escape-avoidance was highly related to anxiety, depression and physical complaints.

2.2. Burnout

The concept of burnout was first introduced by Freudenberger (1974) in relation to front-line human service workers. According to Jackson (1982, cited in Freudenberger, 1989) burnout occurs at an individual level, is usually psychological in nature and is perceived as a negative experience by the individual. Over the years, the concept has come to represent almost any negative reaction to stress in the workplace (Thornton, 1991). There have been multiple conceptualisations of burnout with no definition that has been accepted as standard (Sullivan, 1989). However, Lee and Ashforth (1990) have reported that Maslach's definition has been the one most frequently cited. Maslach (1982) defines burnout as a process involving emotional exhaustion, depersonalisation and reduced personal accomplishment, usually in response to chronic occupational stress. An emotionally exhausted individual feels that they are unable to give of themselves to others. Depersonalisation marks the onset of negative, cynical attitudes and feelings about one's clients. In cases of reduced personal accomplishment the individual tends to evaluate him or herself negatively, particularly in relation to work. In a review of literature relating to job burnout, Cordes and Dougherty (1993) posit that the core dimension of burnout in the initial phase is emotional exhaustion; depersonalisation is the coping mechanism employed in response to this, followed by feelings of reduced personal accomplishment.

According to Maslach (1982), burnout occurs particularly in occupations where a significant proportion of time is devoted to close emotional involvement with others. Maslach (1978, cited in Cordes & Dougherty, 1993) asserts that emotional strain is at its height for individuals in the helping professions because of the constant engagement with people and their problems. Work in the helping professions is characterised by direct face-to-face contact in emotionally charged situations. In many cases, feedback from either the client or the organisation is either non-existent or predominantly negative (Cordes & Dougherty, 1993). Burnout has been implicated in high job turnover, reductions in quality of care and service delivery, and absenteeism (Kilfedder et al., 2001). Most discussions on burnout are drawn from samples in the human service professions such as teachers, nurses, police and mental health workers (Maslach, 1982).

A number of measures have been designed to access the construct of burnout. The most extensively used assessment instrument has been the Maslach Burnout Inventory-MBI (Lee & Ashforth, 1990). The MBI assesses burnout on three scales: emotional exhaustion, depersonalisation and reduced personal accomplishment. Scores on each scale are considered separately and not combined into a single total score (Lee & Ashforth, 1990). A high degree of burnout is evidenced by high scores on the emotional exhaustion and depersonalisation subscales and lowered scores on the personal accomplishment subscale (Maslach, Jackson & Lieter, 1996). The converse is true for a low degree of burnout (Anderson, 2000; Maslach, 1982).

2.2.1. Mediating Factors of Burnout

The phenomenon of burnout is mediated by a complex interaction of factors. Factors repeatedly identified in the literature have been organisational factors, socio-demographic factors and social support. Research on these factors in relation to burnout will now be reviewed.

Organisational Factors

The organisational context and its job characteristics can either promote or reduce emotional distress, thus the organisational context is central to the burnout syndrome (Maslach, 1982). Chiriboga and Baily (1986, cited in, Robinson, Roth, Keim, Levenson, Flentje & Bashor, 1991) found that the work environment and work stressors contributed significantly to burnout. LeCroy and Rank (1987) drew similar conclusions in a quantitative study of 106 social workers; they assert that the source of burnout is more a function of the job situation than a function of the individual person.

Role conflict and role ambiguity have been implicated in the cause of burnout and psychological distress (Raphael, 1990 cited in Barbour, 1994; Cordes & Dougherty, 1993; Siefert, Jayaratne & Chess, 1991, cited in Jansen et al., 1996). Research among health care social workers showed that role conflict, role ambiguity and a lack of physical comfort were significantly related to emotional exhaustion, depersonalisation was related to a high degree of role conflict, low challenges and low satisfaction with poor financial rewards (Siefert et al., 1991, cited in Jansen et al., 1996). In a study of 135 female human service professionals, Brookings, Bolton, Brown and McEvoy (1985, cited in Cordes & Dougherty, 1993) reported statistically significant relationships between perceived role conflict and role ambiguity and all three burnout components. Although only a few studies have investigated role conflict and ambiguity in relation to burnout, the existing findings remain consistent (Cordes & Dougherty 1993).

Inadequate funding, limited resources and poor financial compensation take their toll on caregivers, predisposing them to burnout. With regard to financial compensation, Edlewich and Brodsky (1980, p. 16) remark, "The person who sets out to help others pays a price in economic well being. So does the person's family, and the deprivations suffered by ones loved ones can have obvious personal and emotional repercussions".

According to McKusick & Horstman (1986 cited in Catalan, Burgess & Klimes, 1995) a substantial proportion of total working time spent working with PWAs is a potential risk factor in burnout. Spending 60 per cent of the working week on HIV has been claimed to be the threshold for avoiding psychological distress (Miller, 1988 cited in Catalan et al., 1995). In slight contrast to the above findings, a review of fifteen studies on organisational stress in relation to burnout in nurses, concluded that burnout is a more likely consequence of stressors related to the workplace than stressors related to interactions with patients (Duquette et al., 1994).

Socio-Demographic Factors

With regard to demographic factors, previous studies have identified a relationship between age and burnout (Rapheal et al., 1994, cited in Barbour, 1994; Kilfedder et al., 2001; Maslach, 1982; Miller, 2000 & Robinson et al., 1991). Kilfedder et al. (2001) in a study on psychiatric nurses found high levels of depersonalisation among younger employees. Robinson et al. (1991) reported similar findings in a sample of 314 nurses in different disciplines of nursing. The authors (Kilfedder et al., 2001) speculate that this could be the consequence of an initial shock to job reality, a lack of adaptation to, or the insecurity of working life, or that those who remained over a longer term were those that did not burn out. Another probable reason for this may be that older providers are more experienced, stable and mature, probably with a more balanced perspective on life, all of which serve to render them less prone to burnout (Maslach, 1982).

With regard to gender, Maslach (1982) noted that females appeared more susceptible to emotional exhaustion, experiencing it more intensely. Kilfedder et al. (2001) assessed burnout in 510 psychiatric nurses, with the use of self-report questionnaires of occupational stress and the MBI. They concluded that male nurses reported more depersonalisation than female nurses. Maslach (1982) made similar observations stating that depersonalisation occurred more frequently amongst men, who in general displayed more callous feelings toward the people they worked with (Maslach, 1982). Maslach (1982) accounts for this difference by referring to traditional gender roles.

In a review of the literature, Etzion and Pines (1986) conclude that previous studies have showed that women report more burnout than men. Adopting a social psychological perspective, Etzion and Pines (1986) argue that burnout is not the result of dispositional attributes of men or women but rather situational features that occur as a result of cultural differences. In their own study of 503 human service professionals in the United States and Israel, and with the use of self report questionnaires measuring coping and burnout, Etzion and Pines (1986) observed that woman reported feeling more burnt out than men. They attribute this to the fact that most professional woman carry the burden of two full time jobs, namely career and domestic commitments. They highlight the relationship between coping and burnout, asserting that women in both cultures prefer less effective coping strategies. They argue that the choice of coping strategy is influenced by sex role stereotypes that exist in one's culture. In this regard, girls are socialised to behave in a manner that is less assertive, less active, more dependent and more conforming than boys (Etzion & Pines, 1986).

A significant relationship has been observed between burnout and marital status. According to Maslach (1982), single providers experience the highest level of burnout as opposed to married providers who experience the least levels of burnout. Cordes and Dougherty (1993) caution against this assertion and argue that more evidence in this regard needs to be obtained. Being childless was also associated with burnout; professional helpers with children appeared to be less prone to burnout (Maslach, 1982). The underlying assumption is that people with families are often older, mature adults and their involvement with spouses and children equip them with the experience in dealing with emotional conflicts and personal problems (Maslach, 1982). In addition, families are a source of support providing affection and approval. Maslach (1982) speculates that practitioners with families have less reason than single individuals to seek personal gratification through emotional entanglements with recipients of care.

In a review of studies investigating the relationship between burnout and socio-demographic factors, Duquette et al. (1994) concluded that demographic factors other than age do not play a significant role in the onset of burnout in nurses, as demographics have not consistently been related to burnout.

Personality

According to Maslach (1982), situations are marked by the equal exchange of individual characteristics and situational variables. These characteristics include personal motivation, needs and style, self-esteem, as well as emotional expressiveness and control. Maslach (1982) adds that these qualities may account for why some individuals are more susceptible to burnout than others. Edelwich and Brodsky (1980) assert that one reason why individuals are attracted to the helping profession is to confirm their own sense of power by some noticeable impact over the world, burnout occurs when this wish is frustrated either by organisational factors or the projection of one's own helpless feelings or needs onto the client's situation.

Neurotic traits may act as a vulnerability factor predisposing individuals to experience burnout (Schaufeli, 1999 cited in Kilfedder et al., 2001). Kilfedder et al. (2001) observed that high levels of emotional exhaustion and depersonalisation were associated with higher negative affectivity and lower positive affectivity. They concluded that individuals who more frequently reported stress and health complaints and had less of a tendency to be socially and physically active were more prone to burnout (Kilfedder et al., 2001).

In a study on critical care nurses, Boyle, Grap, Younger and Thronby (1991, cited in Jansen et al., 1996) found that personality hardiness was related to burnout. Personality hardiness comprises three dimensions: commitment, challenge and control. Individuals described as personality hardy have a high sense of commitment to their work and selves, with greater control over their lives, viewing stressors as challenges with potential opportunities for change rather than threatening to their security (Duquette et al., 1994; Topf, 1989). In a review of six studies investigating the relationship between personality hardiness and burnout, Duquette et al. (1994) reports that there exists a negative relationship between hardiness and burnout in nursing personnel, whereby nurses with hardy personality traits (Challenge, commitment and control) are less likely to burnout. However, in a study of personality hardiness and occupational stress in relation to burnout in critical care nurses, Topf (1989) concluded that the study did not provide support for the stress buffering effect of personality hardiness.

Social Support

Maslach (1982) asserted that problematic peer interactions could leave one vulnerable to burnout in two ways: Such interactions become an additional source of stress exacerbating levels of emotional exhaustion; and the individual is robbed of a valuable resource for coping with and preventing burnout.

Research has consistently found that social support is negatively related to burnout (Bennet et al., 1994; Duquette et al., 1994; Jansen et al., 1996; Maslach, 1982; Miller, 2000; Munley, 1985; Ogus, 1992). For example, Ogus (1992) in a comparative study on burnout and coping in medical and surgical ward nurses illustrated that higher levels of emotional exhaustion and depersonalisation were associated with less available social support. The converse is true in situations where there is greater availability of social support and high levels of satisfaction with such support (Ogus, 1992).

Support from supervisors and from other non-work relationships was cited as a crucial factor assisting nurses in coping with job related stressors (Jansen et al., 1996). Social support acts as a protective factor against burnout; it provides an opportunity for expression of feelings, minimising one's sense of isolation (Duquette et al., 1994). However, it can also have a negative impact, Munley (1985) in a qualitative study on hospice staff observed that staff interaction was a major source of stress due to the high expectations hospice staff had of one another. Creating support structures through role modelling aimed at orientating new staff became the source of self-generated guilt (Munley, 1985). Social support appears to be an important factor in combating burnout, however it is the quality of the interaction between friends, family and colleagues that determine whether the support received will ultimately exacerbate or minimise the risk of burnout.

The causal relationship between burnout and poor social support remains unclear. While social support may alleviate burnout, burnout may have damaging consequences on one's support structures. Lynn (1989, p. 24) alludes to this stating that, "Stress generated by work can permeate into our private lives. It can affect all those relationships on which we depend on for restoration".

2.3. The Relationship Between Coping and Burnout

The literature on burnout and coping consistently illustrates that coping strategies can either minimise or increase burnout. The following section will briefly review these findings.

From results obtained on the MBI and Ways of Coping Scale, Celowitz (1989, cited in Duquette et al., 1994) conclude that high levels of burnout were apparent in nurses who utilized escape and avoidance, self-controlling (inhibiting the expression of feeling), and confronting as coping strategies. These findings are consistent with a study assessing the relationship between coping, appraisal and burnout in a sample of 234 full time mental health workers, which found that escape-avoidance was related to all three symptoms of burnout (Thornton, 1991). Findings by Etzion and Pines (1986, cited in Thornton, 1991) support Thornton's findings, that the use of inactive coping strategies, such as avoidance and medication are positively related to burnout.

In the context of community health-care, Martin and McGuire (1990, cited in Jansen et al., 1996) found that individuals experiencing higher burnout scores more often used mental and behavioural disengagement as a primary coping technique. This occurrence was more common in less experienced nurses; more experienced nurses were less likely to engage in activities aimed at mentally distancing themselves from the stressful situation.

It has been suggested that emotion-focussed coping strategies increase the likelihood of burnout (Carver et al., 1989; Dewe, 1993; Gueritault-Chalvin, Demi, Peterson & Kalichman, 2000; Miller, 2000). Emotion-focussed efforts may be maladaptive because they focus on the source of stress, thus exacerbating it, and prevent the individual from actively addressing the problem (Carver et al., 1989, cited in Payne, 2001). Interestingly, Payne (2001) discovered that both emotion-focussed and planful-problem solving was associated with lower levels of burnout. In this regard, emotion-focussed coping did not constitute negative actions such as escape or accepting responsibility, but instead aimed at creating positive meaning by focussing on personal growth. Many of the stressors in nursing are not amenable to change; as a result emotion-focussed efforts may form an important part of coping (Boyle, 1989 cited in, Payne, 2001). Pines, Aronson & Kafry (1981, cited in, Thornton, 1991) found that active coping (i.e. problem-focussed coping) was associated with lower levels of burnout. Pines et al. (1981, cited in, Payne, 2001) concludes that the individual who copes best is the one who employs the most effective coping strategy specific to a particular context. For example, planful problem solving in the case of hospice workers dealing with issues of death and dying may be counterproductive.

Kilfedder et al. (2001), in a study of burnout in psychiatric nurses, found that lower levels of personal accomplishment were associated with less control over job related events and less use of coping strategies. Shaufeli (1999, cited in Kilfedder et al., 2001) adds that reduced personal accomplishment is usually associated with an avoidant coping style.

Shinn, Rosario, Morch and Chestnut (1984, cited in, Thornton, 1991) found no relationship between coping efforts and burnout. Thornton (1991) and Duquette et al. (1994) both report that empirical studies designed to investigate the relationship between coping efforts and burnout yield inconsistent findings, possibly because they fail to consider the role of the individual's appraisal of the stressor in relation to burnout. Duquette et al. (1994), reviewing studies on coping in relation to burnout, indicates that it is difficult to draw conclusions as the majority of investigations utilise different instruments.

The preceding section clearly illustrates that numerous studies have observed a relationship between coping strategies (problem/emotion-focussed) and burnout, which either predispose or alleviate the risk of burnout in caregivers.

2.4. Burnout in the Context of HIV/AIDS

The following section reviews the literature on burnout in the context of HIV/AIDS care. While the preceding discussion on mediators of burnout is equally applicable to the HIV/AIDS context, additional features salient to the epidemic may compound the experience of burnout.

The argument that HIV/AIDS poses unique challenges that differ in relation to other medical conditions has been contested (Klieber et al., 1992 cited in Miller, 2000). Few studies however have attempted to compare the challenges of HIV/AIDS work to other fields of healthcare (Miller, 2000). Bennett, Michie and Kippax (1991, cited in Barbour, 1994) compared the factors associated with burnout for AIDS nurses and for oncology nurses, finding that while AIDS nurses did not suffer emotional exhaustion as often as their oncology counterparts, they were prone to greater intensity of emotional exhaustion when this did occur. Research in this field remains sparse and limited conclusions can be drawn from the exiting literature (Miller, 2000).

Van Dis and Van Dongen (1993, cited in Miller, 2000) suggest that unique characteristics of HIV/AIDS care include: Secondary stigmatization, a high level of emotional identification with patients, and fear of HIV/infection.

A common concern among health care workers is the fear of stigmatization as a result of caring for PWAs. Monodwafa, Bower and Webb (1993, cited in Horsman & Sheeran, 1995) compared nursing students in the United Sates (U.S.) and Zimbabwe. They found that 30% of their U.S. sample were concerned that people would think they were homosexual if they contracted AIDS, while 74% of Zimbabwean sample were worried that people would think they were prostitutes. Horsman and Sheeran (1995, p. 1546) state: "These findings underline the significance of shared cultural understandings of HIV/AIDS and the importance of challenging specific local fears in educational interventions."

In a descriptive study on community based HIV/AIDS care and support in South Africa, community health workers felt that confidentiality rendered them invisible because they could not admit to providing AIDS services (Michele & Schneider, 2000). One caregiver reported that a colleague would not drive into the township with the Red Cross insignia on her car as people began associating it with AIDS home-based care and subsequently were reluctant to have the colleague visit them for the fear of being victimised (Michele & Schneider, 2000).

As indicated in the preceding section, while social support may be an important factor in alleviating burnout, Bennet et al. (1994) stress the importance of understanding the context in which such support is offered. The social focus on HIV/AIDS may buffer against or accentuate burnout depending on whether the work is viewed positively or whether health workers in the field are stigmatised. In a study on the relationship between stigma and burnout, the authors concluded that negative social attitudes lead to an increase in burnout (Bennet et al., 1994). Horsman & Sheeran (1995) report similar findings in a review of the literature on health care workers and HIV/AIDS, concluding that health care workers found that having their friends and family know that they take care of PWAs was a significant stressor. Hospice nurses in a support group reported being ostracised by friends and feeling isolated from previous sources of support since caring for PWAs (Greif, 1993, cited in Horsman and Sheeran, 1995). Bennett et al. (1994) made similar observations in a study of burnout and its associated factors amongst health care professionals providing HIV/AIDS care, demonstrating a relationship between stigma and burnout.

Green and Miller (1987, cited in Miller, 2000, p. 72)) state that: " HIV/AIDS staff are required to cope with the stress of identifying with patients from their own peer groups, with the grieving of patients, their loved-ones and families, and with concerns about HIV in a social context of potential stigma and ostracism". The issue of death and dying has been identified as a significant stressor and mediator of burnout in the HIV/AIDS context (Miller, 2000). In the U.S., gay physicians were more likely than heterosexual physicians to report increased fear of death and dying with greater levels of anxiety after exposure to AIDS-related work (McKusick et al., 1986 cited in Barbour, 1994). With reference to community health workers in the South African context, issues of association and over identification with recipients may be particularly relevant. Recipients infected are members of the carer's community, sharing a similar background. This may bring the epidemic closer to home for community health workers.

In a review of the literature on health care workers and HIV/AIDS, a shared concern among health care workers was the risk of becoming infected (Horsman & Sheeran, 1995). The fear of infection causes considerable anxiety, which may predispose carers to burnout. Although the risk of being infected is low, it continues to persist (Horsman and Sheeran, 1995). Link, Feingold, Charap, Freeman and Shelov (1988, cited in Horsman and Sheeran, 1995) found that 80% of doctors in their sample estimated the actual risk of infection at less than 1 in 10 000; yet even with such low probabilities of infection, doctors still expressed fear and stress in this regard. The fear of infection continues as exposure to HIV is often accidental; thus even with necessary precautions, risk of infection is not entirely eliminated. Of the 37 documented cases of occupationally acquired HIV world wide, the majority were presumed to have been caused by some sort of needlestick injury. Results from a hospital survey indicated that in a period of a year, nurses incurred 45% of all needlestick injuries (Hayward & Shapiro, 1991 cited in Horsman and Sheeran, 1995). According to Morgan (1990, cited in Horsman & Sheeran, 1995) needlestick or sharps injuries are usually the result of inexperience, lack of rest and work pressure. Given the high rates of HIV infection in South Africa, CHWs are overburdened and work long hours thus increasing the risk of accidental infection. A chronic lack of resources raises the question of whether community health workers in South Africa have access to vital resources such as rubber gloves to minimize the risk of infection, or immediate access to anti retrovirals in the event of exposure to the virus. These questions emphasise the added risk of occupational infection that community health workers in South Africa face.

Identified as a unique characteristic of HIV/AIDS care is the absence of a cure and HIV/AIDS' fatal outcome (Miller, 2000). The intensity of the epidemic and high number of those infected also poses a multitude of challenges; nowhere is this more prevalent than in South Africa. Finally, working in a context plagued by multiple losses and bereavement within peer groups adds to the challenges of working at the forefront of the HIV/AIDS struggle (Miller, 2000).

2.5. Research on Burnout in The South African Context

In an unpublished review of caregiver research in South Africa, Melnick (2002) concluded that the predominant focus has been on the assessment of burnout rather than coping. None of the research in the field of burnout explores the topic in relation to the impact of HIV/AIDS on caregivers; the focus is rather on care within the hospital system (Melnick 2002; Munnik, 2000 & Nixon, 1995). Of the studies exploring caregiver's experiences in the HIV/AIDS context, few have focussed on burnout (Melnick, 2002; Michele & Schneider, 2000; Minnaar, 2001; Uys, 2001).

Bindell (1991, cited in Swartz & Gibson, 2001) reported that the leading cause of burnout was role overload due to multiple roles that CHWs occupy in relation to community health work. Secondly, CHWs work in a context of abject poverty and are often asked to assist with the material needs of patients, even though CHWs themselves are seldom in a financial position to do so, but the desire to respond to these needs can be overwhelming. Furthermore, because CHWs are known in the community, the boundaries between their private and professional lives become blurred (Swartz & Gibson, 2001). These findings are consistent with previous studies documenting the relationship between role-ambiguity and burnout in caregivers (Barbour, 1994; Cordes & Dougherty, 1993; Jansen et al., 1996)

A review of published research in the arena of home-based care and/or its impact on caregivers reveals that this has been a neglected area. Uys (2002) provides a descriptive account of the practice of home-based care in South Africa; the study explores the community context and the perceptions of community health workers providing home-based care. Caregivers identified collegial and supervisory support as fundamental aspects in the implementation and maintenance of the project. In another descriptive study, Michele and Schneider (2000) explored the needs of those infected in a study of PWAs and care providers in an urban township near Pretoria. The study also assessed community-based care and support programmes currently in place. The dominant themes emerging from interviews were poverty and isolation, hunger, difficulty in accessing welfare grants, fear for their children, fear of acceptance and the limited male participation in HIV/AIDS services.

Only one unpublished study has investigated coping strategies of caregivers providing home based care for people with advanced HIV/AIDS infection (Melnick, 2002). Melnick administered the Ways of Coping Scale to 82 caregivers from four home based care organisations. Results indicated that 7 of the 8 Ways of Coping questionnaire subscales were not functioning reliably. In light of this it was recommended that future research adopt a more appropriate methodology given the cross-cultural and cross-linguistic difficulties evident in the study. In a brief qualitative analysis aimed at contexualising the quantitative results, home-based carers identified the use of faith, support from family and colleagues, as well as controlling of their emotions as ways of coping. Additional training, support groups, government support, material support and places of safety for PWAs were areas they felt would assist them to cope better with demands (Melnick 2002).

2.6. Limitations of Research on Burnout and Coping: Implications for the Study of HIV/AIDS Caregivers

The following section reviews the methodological limitations and generalisability of Western research on burnout and the impact of HIV/AIDS care on caregivers.

One of the major criticisms levelled against research on burnout has been the over reliance on self-report measures (Barbour, 1994; Horsman and Sheeran, 1995; Kilfedder et al., 2001; Miller, 2000 & Payne, 2001) The use of self-report measures as opposed to independent ratings or observations, introduces the bias of retrospective distortion or socially desirable responding (Payne, 2001). In addition, this approach implies that respondents identify stressors from a predetermined list, or that the instrument used identifies only those features that bolster the constructs on which that instrument is based (Handy, 1988 & Miller, 1993, cited in Miller, 2000). Burnout measures, for example, frequently have negatively loaded items and therefore only destructive and negative aspects of the work are evaluated (Kahill, 1988 cited in, Miller, 2000).

Qualitative methodology has been proposed as a supplemental approach in research on burnout (Horsman & Sheeran, 1995 & Miller, 2000). Horsman and Sheeran (1995) recommend that in-depth qualitative approaches be utilised to shed light on the implications of being a health care worker in the context of HIV/AIDS. In the absence of a qualitative approach, the complexities of health care work are not fully appreciated and lost by the narrow manner in which issues are framed by researchers. Miller (2000) makes a similar assertion, adding that in order to provide staff support, researchers need a thorough understanding of the HIV/AIDS context, and that such an understanding cannot be derived through the analysis of grouped scores or standardised psychometric scales. Miller (2000) recommends that standardised psychometric instruments be complemented by qualitative data. Interviews, for example, allow the researcher to follow the path the respondent selects in answering structured questions (Gillies, 1991 cited in Miller, 2000).

Barbour argues that research appears to have been built up "serendipitously rather than systematically, with many researchers opportunistically confining their investigations to the hospital or medical centre where they happened to be based…there is no sense that study locations thus selected are truly representative" (Barbour, 1994, p. 223). Eighty percent of research has derived its samples from nurses, doctors, hospitals, and general practitioners, with a limited number of studies on volunteers (Barbour, 1994). In addition, a large volume of research stems from a Western context and cannot easily be generalised to developing countries, where AIDS is at its most severe and resources most lacking (Catalan et al., 1995; Horsman & Sheeran, 1995). There is relatively little research into health care workers who provide home based care and confront aspects of the patients life that may not be evident in the hospital setting (Horsman & Sheeran, 1995 & Melnick, 2002).

The majority of instruments created to measure burnout, coping, stress and other such variables have been developed within a Western context (Miller 2000). The generalisability and use of such instruments in developing countries must be approached with caution. In these instances, the way forward, according to Miller (2000), is the use of structured interviews accompanied by the administration of standardised instruments.

The individualistic nature of burnout research has been another area of criticism (Miller, 2000; Barbour, 1994). A large proportion of studies have failed to contextualise AIDS work or the demands it makes on workers. While attempts have been made to explore stress and burnout in health care beyond the individualistic approach, other areas to consider are organisational, social and cultural factors that may act as potential stressors or buffers (Barbour, 1994). Pearlin (1989, cited in Barbour, 1994, p. 243) states that: "All to often, peoples background and circumstantial attributes are either overlooked in analysis or receive scant attention. Thus data which should be at the heart of sociological inquiry are frequently treated only as analytic noise that needs to be controlled statistically, when social structural and contextual data are collected only so that they may be controlled, that treatment precludes the examination of their potentially important roles..." Qualitative methodology is therefore crucial, as it allows the researcher an opportunity to engage with the complexities and contradictions within the given context and further supplement quantitative research.

Finally, given the cross-sectional nature of most studies on coping and burnout, the relationship between variables can be identified at only one specific point in time. Longitudinal designs, while difficult to execute methodologically, are crucial in furthering our understanding of the development of burnout and the impact of coping in this regard (Payne, 2001).

2.7. Summary of Chapter

This chapter defined the concept of coping, providing a descriptive account of its various dimensions. Burnout was also defined, and its mediating factors considered; these being organisational, socio-demographic, personality and social support. The relationship between coping and burnout was illustrated through a discussion of how various coping strategies may influence burnout. An outline of burnout in the context of HIV/AIDS was provided, followed by a review of burnout research in South Africa, which drew attention to the paucity of such research in the context of HIV/AIDS and home-based care. Finally methodological limitations of existing research into HIV/AIDS care point to the need for a more qualitative approach to burnout and coping research.

CHAPTER THREE

METHODOLOGY

3. Introduction

This chapter illustrates the methodology employed in the present study. It commences with a statement of the research problem. The research design is highlighted, with a description of the sample. A motivation for the use of the MBI in conjunction with a qualitative approach will be provided, and the method of qualitative data analysis discussed. The chapter concludes with a consideration of the role of the interpreter and of ethical considerations.

3.1. Statement of Research Problem

The aims of this study are:

1. To obtain an in-depth understanding of the coping strategies that health care workers providing home-based care to PWA's draw on, in response to stressful work experiences.
2. To explore whether different coping mechanisms are utilised by health care workers at different points on the burnout continuum.

3.2. Research Design

The study adopts a cross-sectional design, and integrates both quantitative and qualitative research methodology. The data collection was a two-phase process. In the first phase, the MBI was administered to a group of health care workers in an organisation providing home-based care. Results obtained from the MBI were analysed. Those participants on the highest and lowest ends of the burnout continuum were identified based on their scores on the emotional exhaustion scale (EE) of the MBI (Maslach et al., 1996). The second phase of the data collection process adopts a case study approach, aimed at gaining insight into coping strategies. This entailed interviews with 12 participants, divided into 2 groups: The High Burnout Group contained individuals with the highest burnout scores and The Low Burnout Group contained individuals with low burnout scores. Semi-structured interviews were conducted, utilising open-ended questions to explore the various coping strategies utilised by health workers in each group. This section is based on a hermeneutic approach to knowledge.

The present study attempts to understand the intricacies of the experience of providing home-based care through a case study approach. In this regard, hermeneutic phenomenology presents itself as a useful philosophical and methodological approach. Geanellos (2000) states that the central premise of hermeneutical phenomenological research is the attempt to understand or gain insight into human experience. According to Kelly (1999) hermeneutics is the study of the interpretation of texts, the purpose of which is to obtain a common understanding and meaning of a text. Within this phenomenology, the researcher undertakes, to not only objectively describe the experience of participants but also to present an interpretation of the phenomenon described, informed by the researcher's own experience and theoretical framework. In order to achieve this the researcher has to engage with participants, develop an understanding of the social setting and "see things through their eyes" (Bhana & Kanjee, 2001, p. 143). Thus hermeneutic phenomenology has both a descriptive and interpretive element (Heidegger, 1962 cited in Van der Zalm & Bergum, 2000).

Gelvin (1989, cited in Robertson-Malt, 1999, p. 290) defines hermeneutic phenomenology as "…as analysis by which the meaning of the various ways in which we exist can be translated from the vague language of everyday existence into the understandable and explicit language of ontology without destroying the way in which these meaning manifest themselves to us in our everyday lives". Robertson-Malt (1999) asserts that hermeneutic phenomenology respects the capacity of the individual as self-knowing. A philosophical approach of this nature aims to create a much-needed space to give voice to community health workers experience of providing HIV/AIDS care within an impoverished context. Given the salience of the HIV/AIDS context, the hermeneutic approach is particularly well suited as it locates and understands the individual within their context (Robertson-Malt, 1999).

Kvale (1996) speaks of the hermeneutical circle; a methodological device which entails understanding parts of the text and its various themes in relation to the totality of the text, i.e. understanding the sum of the parts that form the whole. This allows the interpreter to gain a deeper, more comprehensive meaning of the text.

Unlike the positivist approach to knowledge that underlies scales like the MBI, hermeneutic phenomenology does not assume an objective "truth"; instead "truth" is co-constructed by participant and researcher, within a context. An integration of these multiple "truths" and an understanding of them leads to the creation of knowledge. Knowledge in this context may be regarded as "fluid and embedded within a meaning system of people; they are not impartial, objective and neutral" (Neumna, 1997, cited in Bhana and Kanjee, 2001, p. 143). Phenomenological descriptions may be challenged by other understandings, informed by an ever-changing society (Van der Zalm & Bergum, 2000). Thus a phenomenological approach of this nature leaves room for alternate descriptions (Anderson, 1991 cited in Van der Zalm & Bergum, 2000). "As a result, a full explanation of the world is not possible nor is it possible to obtain causal certainty and inference, or the production of law like statements" (van Manene, 1997a cited in Van der Zalm & Bergum, 2000, p. 212).

The hermeneutic position has been criticised for an over emphasis on interpretation, with limited focus on addressing oppressive conditions (Usher, 1996b, cited in Bhana & Kanjee, 2001). This is particularly salient in communities where the need for social action is more pressing than the need for additional information. The present study has highlighted the paucity of research with regard to CHWs coping styles in relation to burnout, thus before social action can be implemented there has to be an understanding of CHWs experience of proving home-based care.

Given that the methodologies utilised are applicable to specific individuals and groups, hermeneutic phenomenology has been criticised for the lack of generalisation of its findings. The present study recognises the limitations in this regard and does not attempt to characterise all CHWs experiences, other than those in the present study. Finally the subjective nature of interpretation casts doubt on whether research outcomes reflect actual reality or the researcher perception thereof. In response to this Bhana and Kanjee (2001) utilise the concept of 'bracketing', which requires that the researcher reflect on his/hers personal views and feelings and how it may impact on the research.

This mixed design was considered appropriate because it addressed the main criticism of burnout research, being the over reliance on self-report questionnaires (Barbour, 1994; Horsman & Sheeran, 1995; Miller, 2000; Kilfedder et al., 2001, Payne, 2001). Although the present study makes use of a self-report questionnaire (MBI), it does so in conjunction with in-depth qualitative data. Based on Miller's recommendation (2000), this study aims at complementing quantitative data on burnout with qualitative data in order to openly explore the coping strategies that might be associated with burnout amongst CHWs working with PWAs.

3.3. Sample

Participants were selected from The Caring Network in Cape Town, a Catholic based community outreach programme servicing Crossroads/Nyanga, Wallacedene, Driftsands, Phillipi, Site B, Mfuleni, Mbekweni and Bishop Lavis. Forty-five CHWs responded to the MBI; administrations took place in four separate groups in the various areas. Two groups of six participants were selected from the highest (High Burnout Group) and lowest burnout (Low Burnout Group) scores and were matched as far as possible, in terms of gender, age, marital status and number of dependants in order to minimise the possible role of demographic mediating factors. Participants were all Xhosa speaking; therefore a translator was used for both the group administration of the MBI as well as individual interviews.

3.4. Instruments

3.4.1. Demographic Questionnaire

Participants were requested to provide the following demographic details: gender, age, home language, marital/cohabitation status, dependants and combined monthly earnings. This information was used to ensure that the High Burnout Group and the Low Burnout group matched as far as possible on those demographic factors, which have been associated with burnout in the literature.

3.4.2. Maslach Burnout Inventory

Consisting of 22 7-point Likert scale questions, the MBI has consistently been used to assess the construct of burnout (Lee & Ashforth, 1990). The MBI is not designed to assess the presence or absence of burnout per se, but rather levels of burnout existing on a continuum (Maslach et al., 1996).

Nine items assess emotional exhaustion. Scores between 0-19 reflect low emotional exhaustion, 19-26 is considered average, while those exceeding 26 constitute high emotional exhaustion. For depersonalisation, measured by 5 items, scores under 6 are considered low, between 6-9, average, and scores beyond 9 characterise high depersonalisation. Eight items assess levels of personal accomplishment; scores over 39 characterise high personal accomplishment, an average on this scale will be reflected by scores between 34-39, with reduced personal accomplishment on scores below 34 (Maslach et al., 1996; Robinson et al., 1991).

The MBI has relatively high internal consistency and test-retest reliability with promising results pertaining to its concurrent and predictive validity (Payne, 2001). Reported internal reliability coefficients for the subscales are as follows: .90 for Emotional Exhaustion (EE), .79 for Depersonalisation (DP), and .71 for Personal Accomplishment (PA) (Maslach et al., 1996). Test-retest reliability coefficients were: 0.82 for EE, .60 for DP, and .80 for PA (Maslach et al., 1996). The normative sample for the MBI includes American social security administration employees, nurses, teachers, police officers, agency administrators, counsellors, social workers, physicians, probation officers, mental health workers, psychologists, psychiatrists and attorneys (Finch & Krantz, 1991).

Correlations between Maslach scores and the Crowne-Marlow Desirability Scale were not significant, indicating that burnout responses do not appear to be influenced by social desirability responses (Cordes & Dougherty, 1993).

Ethnic background is a particularly salient feature in the present study and worth considering in relation to the MBI. Maslach characterises burnout as the "white experience" (Maslach, 1982, p.57), acknowledging that the vast majority of participants studied have been white Americans. Maslach (1982) found that the Asian American experience of burnout was similar to the white experience, however dramatic differences were noted between African American and white carers. African American carers experienced far less emotional exhaustion and depersonalisation. Maslach (1982, p. 57) speculates that, "One possibility is that they (African Americans) come from communities in which there is a greater emphasis on family and friendship networks and on direct, one-on-one relationships with people. *Rapping* with each other involves emotional expression, confrontation, personal feedback, and resolution of conflicts; there is also more assertiveness and spontaneity." Consequently African Americans may be more experienced in dealing with people especially in emotionally charged situations. Furthermore due to their own experience of poverty and discrimination, African Americans may be more prepared to deal with problems and pain (Maslach, 1982). Maslach's arguments may reflect some degree of racial stereotyping; this suggests that the reasons for lower burnout in the African American group still have to be established. Despite Maslach's findings, separate norms for African Americans were not created. In South Africa, the Human Science Research Council has no record of published MBI data for South African health care workers (Nixon, 1995). The lack of local norms is not considered a problem in the present study, as groups will be generated through comparing participants to each other and not to existing norms per se.

In South Africa, the MBI has been used to assess burnout among church ministers, university teachers and teachers in a school settings (Florence, 1998; Pretorius, 1992 cited in Munnik 2000; Odendal & van Wyk, 1988 cited in Munnik, 2000). Previous South African research employing the MBI cross-culturally within the health profession did not seem to identify its limitations in its use across cultures (Munnik, 2000). However in a sample or surgical nurses, where 47% were Afrikaans speaking and an additional 7% Xhosa speaking, Nixon (1995) identified the administration of the MBI in English as a possible limitation. In the present study, all the participants are first language Xhosa speakers. As such it was decided to translate the MBI into Xhosa in order to enhance the instrument's validity. To date this has been the only South African study to utilise a translated version of the MBI.

In the present study the internal consistency was estimated by the Cronbach's coefficient alpha (n=45) at .69 for EE, .77 for DP and .68 for PA.

3.4.3. Semi-Structured Interview

Kelly (1999, p. 398) describes qualitative methodology as, "a turn towards 'contextual' research which is less immediately concerned with discovering universal law-like patterns of human behaviour, and is more concerned with making sense of human experience from within the context and perspective of human experience". Within the framework of this methodology, semi-structured interviews create the opportunity to explore issues that may be too complex to address quantitatively. They allow for the integration and understanding of inconsistent and contradictory views, which may not necessarily reflect faulty reasoning but rather real contradictions (Banister, Burman, Parker, Taylor & Tindall, 1994). Interviews give the researcher an opportunity to follow up on issues raised by the interviewee including areas that may not have been anticipated (Gillies, 1991 cited in Miller, 2000). The semi-structured interviews formed the phenomenological texts upon which the process of hermeneutic analysis was made.

Research of this nature demands reflexivity in the research process. This entails maintaining an awareness of one's role as a researcher, how one is perceived by the interviewee, and ongoing reflections on the process. In addition, structural power relations may exist between the researcher and participants (Banister et al., 1994). Issues of race, class, gender and age may shape the power dynamic (Banister et al., 1994). Consequently, information obtained may not necessarily be a "true" reflection of participants' experiences but rather a response shaped by real and/or perceived power dynamics that may exist within the interviewer-interviewee relationship.

The interview schedule was designed to elicit participants' coping responses in various situations. It contained open-ended questions, which provided a flexible frame within which additional questions could be asked. This gave the researcher the opportunity to follow-up on participants' thought processes by asking questions, while using the interview schedule as a guide. As such this did not limit participants in the expression of their views, as would have a structured questionnaire.

3.5. **Procedure**

The researcher approached co-ordinators and trainers from the organisation, and requested permission to conduct the research. Once permission was granted, the researcher, along with a translator, gave a brief, non-specific overview of the proposed study at the organisation's quarterly meeting. Health care workers were informed that they would be participating in a study of their experiences of their work. Thereafter the MBI was administered to the participants in different geographical areas. According to a recommended procedure (Brislin, 1986 cited in Swartz, 1998), the MBI was translated into Xhosa by one translator and back translated into English a by an independent translator (Brislin, 1986 cited in Swartz, 1998). Drennan (1992) explains back-translation as "a process where the basic translation sequence is reversed and the target version is rendered into the source language by the translator who is "blind" to the contents of the source version. The second source version then serves as a check on the basic translation product" (p. 6).

In the present study the MBI was translated and back translated twice by 2 pairs of translators to ensure that the Xhosa translations were conceptually identical to the original English version. The team of translators then discussed discrepancies until consensus was reached on the optimal version for these items.

Respondents were asked to complete the questionnaire in the presence of the researcher and translator, who provided assistance and answered questions where applicable. The 7-point Likert scale, a self-report format is a Western construct and possibly unfamiliar to the sample, thus practice examples were given in order to orientate participants with regard to responding to the MBI. The results obtained informed selection of participants for the in-depth interviews. A translator was used in all the interviews. Each interview was audio taped, and transcribed.

3.6. Method of Data Analysis

MBI scores were used to select high and low burnout participants, and descriptive statistics for each group on the three subscales were established. With regard to the analysis of interviews, texts were read and re-read to elicit core ideas, concepts and themes. In these early phases of coding, data was placed into preliminary coding categories in order to establish whether such categories provided a good fit to the data. Following this a more formal coding process was undertaken, bringing together fragments of text to create categories, in order to make possible the reduction of texts into analysable units (Coffey & Atkinson, 1996). The integration of one or more of these categories generated themes later discussed in relation to each other, to the broader notions of coping and burnout and to the MBI scores for each group (Rubin & Rubin, 1995).

3.7. The Role of the Interpreter in Cross-Cultural Research

The present study is one of a few studies making use of an interpreter within the context of burnout research; thus the role of the interpreter within the South African context is considered here.

Interpreters perform a vital function in cross-cultural research, however formal aspects of the interpreter's functioning and the difficulties associated with the process have received little attention (Drennan, 1992). The core characteristics of a good interpreter within a clinical context are competence in both languages, familiarity with the patient's culture and familiarity with clinical psychiatry (Marcos, 1979, cited in Drennan, 1992). The interpreter utilised within the current study has considerable experience in translation within a clinical setting and has exposure to home-based carers.

The most common mistakes made by interpreters include omission, addition, condensation, substitution and role exchange (Vasquez & Javier, 1991 cited in Swartz, 1998). While the first four are self-explanatory, role exchange occurs "when the interpreter takes over the role of the interviewer and substitutes the interviewer's questions with those of his own" (Vasquez & Javier, 1991 cited in, Swartz, 1998, p. 40). Problems of this nature stem from a lack of clarity with regard to the interpreter and researchers roles (Vasquez & Javier, 1991 cited in, Swartz, 1998). Swartz (1998) makes some practical suggestions for improving interpreted interviews. In preparing for the interview clarification of the respective roles of interviewer and interpreter is necessary. Swartz (1998) suggests that having the interpreter take notes during the interview may provide helpful data with regard to non-verbal cues. This was not feasible in the present study as the translator had to be focussed on the participants at all times, which left little room for additional note taking. Discussions after the interview are also useful as it allows researcher and translator to share their perceptions of what had transpired in the interview (Swartz, 1998). Swartz (1998) highlights that this sharing of information is better facilitated by an atmosphere of mutual trust and respect between the researcher and translator. In order to achieve this the researcher, as in the case with participants, needs to be aware of the power dynamics that that may emerge between the researcher and translator due to status, race, class or gender. In the present study the researcher and translator shared their impressions of interviews, which not only facilitated a better working relationship, but due to the traumatic content of some interviews, gave both the researcher and translator an opportunity to process such material.

3.8. Ethical Considerations

With regard to the administration of the MBI, informed consent was obtained from participants and their participation was voluntary. For individual interviews, participants each signed a consent form that provided an overview of the research and guaranteed confidentiality. Copies of the thesis will be provided to the Caring Network, but in the discussion of results respondents will remain anonymous with the removal or disguising of identifying details.

3.9. Chapter Summary

The preceding chapter provides a detailed discussion of the methodology employed in the present study. Included in this has been a discussion of the MBI, and its relevance to the South African population. A discussion of the use of semi-structured interviews in the context of a hermeneutic phenomenology was also presented. The method of analysis presented an overview of the coding process for qualitative findings. Attention was drawn to the role of interpreters in cross-cultural research with its various implications, with a final note on ethical considerations.

CHAPTER FOUR

RESULTS AND DISCUSSION

4. Introduction

The context of community health care in the areas sampled by the present study is characterised by poverty, high unemployment, crime, domestic violence and death. In this context one trainer reported that Wallacedence had the highest infant mortality rate in the country. Patients in this context live in abject poverty, are usually too ill to work, and consequently cannot meet their basic needs.

CHWs conduct home visits daily; they work, on average, four hours a day commencing at 9:00. Their workday usually begins with prayer after which time CHWs begin home visits. They walk from home to home throughout the year covering vast distances daily. CHWs generally manage patients, who have suffered strokes, are diabetic, suffer from rheumatoid arthritis, tuberculosis and HIV/AIDS. The distribution of these patients and individual caseloads vary, with some carers treating more HIV/AIDS patients than others.

With this in mind a thematic analysis will highlight similarities and differences between the High Burnout and Low Burnout groups, and attempt to interpret the MBI scores obtained by each group.

4.1. MBI Scores

The mean scores for the three subscales between the High and Low burnout group are shown in Table 2.

Table 2: Mean MBI Scores			
High Burnout Group (n=6)		**Low Burnout Group (n=6)**	
Emotional Exhaustion	37.5	Emotional Exhaustion	9.6
Depersonalisation	11.5	Depersonalisation	0.16
Personal Accomplishment	43.16	Personal Accomplishment	42.5

The results indicate that both groups differ considerably for scores on EE and DP with a negligible difference for PA, which fell in the "high" range for both groups. These results will be considered in the context of qualitative findings.

4.2. Thematic Analysis

From interviews with participants, themes have been grouped under two broad headings: Shared experiences between the High and Low Burnout groups and Differences between High and Low Burnout groups. Quotes from various participants will be presented; in this regard participants from the High Burnout group will be identified as HP1-6, with those in the Low Burnout Group being represented by LP1-6. Due to the use of a translator, certain quotes have been presented in the third person. Where applicable, themes will be discussed with reference to the existing literature on coping and burnout, but in cases where themes extend beyond this framework, additional relevant literature will be drawn on to interpret the themes.

4.2.1. Shared Experiences Between the High and Low Burnout Groups

Both the High and Low Burnout group were exposed to a context in which they confronted similar sources of stress. In addition participants from both groups were unable to articulate their emotional needs, discussed in the following theme.

"Beyond the call of duty"

This theme is concerned with the role ambiguity experienced by CHWs throughout the sample. Carers official duties include collecting and administering medication to patients, cleaning homes, bathing and feeding patients, as well as counselling and educating both the patient and their families. In addition, they also provide psycho-education within the community and at schools. These quotes from CHWs describe their day-to-day duties:

> "…if you have to bath or clean the person, you do that, when you have finished bathing the person, sometimes you notice that the person is alone and there is no one to care for the patient, there is no one to clean the house, to bath, to feed, or to give treatment, so you do all that." LP2
>
> "…and after that I sit with the patient and find out how the patient is doing, and just to keep company, for the patient not to feel lonely". LP3
>
> "We go to the homes, we talk to them and give them support, we encourage them and tell them that this is not the end of the road, and most of them, in their fourth stages, and they could not do anything for themselves, we bath them, turn them, make the bed and feed them." LP4
>
> "We come here at 9:00, we register and after that we go to the homes. It depends on the patients condition, if they are bed ridden you get to the house, you check the house, you clean the house and you warm water for bathing, for those who need to be bath(ed), who have bedsores. And you give them treatment and you ask them how they are doing and if they have not eaten, you must first give them food and then treatment." LP5
>
> "You do anything, sometimes you clean the room, its in our code of work, so you do everything to help them…the first thing you must ask the family of the patient, of the sick person, because some of them they don't have family, they last to see (saw) their family ten years ago." HP1
>
> "…I am helping the community and as a health worker we go (to) the clinics and teach people and give them information and for instance the TB patients, their rate has dropped because we are giving people the information." HP5

CHWs are also responsible for transporting patients to and from the clinic either by wheel chair or if possible, by arranging transport; they also liase with Sisters at the clinic regarding general case management of patients.

However CHWs often go beyond the call of duty, in a context where patients often invest all their hopes of change and recovery with the caregiver. CHWs provide additional support to patients and family. The following carer described how she opened an account with a local store allowing her to purchase food items for her patients, on credit. This usually occurred when she was unable to afford items on cash; she would settle the account at the end of each month:

> "I keep a record because when I do not have money…I spoke to one of the spaza shops where the family could go and take some stuff on credit, than you have to pay at the end of the month. I pay cash sometimes…I also take from my own stuff, like the ten eggs that were provided by one of the counsellors for my children, so I had to share it with that family." HP1

The next quote captures the carer's sense of commitment and duty to her patient. Even in death she ensures that the patient retains their dignity by providing an adequate burial:

> "Its very sad, because some patients don't even have insurances, so the carers have to go around and ask for donations…If the family can't afford, or they poor, or they don't have anything, the carer takes the responsibility to help the family." LP6

The next illustration highlights the carer's concern for the deceased patient's children long after the patient's death:

> "…There is another one who passed away in January, and she had two children and (they) are in the care of the grandmother who is not getting the pension grant, also they are suffering, so sometimes the grandmother would ask me to get some food, proper food…I would go to the clinic and get some food". HP3

After the passing of a patient, CHWs provide emotional support to the family by being present at night vigils, prayers and funerals. Carers reported visiting family members long after the patient had passed away, as a way of helping both the family and themselves come to terms with the loss. In response to questioning on a carer's reaction after the death of her patient, she stated:

> "I often visit the house and talk to the daughter, we would talk about the mother and the work that she was doing and we would laugh and joke about some things the patient did." HP3

> "What makes me feel better, is when the person has died, is to attend the night vigils, in our culture, you take about one week to two weeks before the person is buried, so you attend those evenings those night vigils." LP1

> "...its not easy for that pain to go away, because you are talking to the family, because you care for the patient, so you have to take care of the family after the patient has died and talk to them." LP3

The predominant focus of burnout research has been on carers within the hospital setting (Barbour, 1994; Catalan et al., 1995; Horsman & Sheeran, 1995) Unlike carers in hospital settings, CHWs in this sample are not only responsible for their patient, but invariably become responsible for anxious family members. CHWs often find themselves in the middle of familial conflict, perceived either as a threat or an ally. Either way, carers become mediators, reuniting families, resolving conflicts or becoming family to destitute patients. In the following examples carers reflect on the difficulties encountered in relation to family members:

> "Another problem is the family members, or someone who cares for the patient at home, so when you get there as a carer you find difficulties, because you giving your own messages and treatment, but they get different messages from the family members, they (family members) are not trained and do not know much about this disease, it makes it difficult. Sometimes the patients don't get better treatment from the family, they swear at them...What I did not like was when I was trying to talk to the patient, the sister would intervene and tell me about their problems, there is some sibling rivalry and the patient took the sisters money and went to Johannesburg...now she has come back sick. So it was more of me having to listen to their problems rather than focus on the patients condition...And it is something that happened long, long ago and it was not a good time to raise it. It was painful for me because I did not get enough time to care for the patient and first of all I did not get a good reception from the sister." LP3

> "(Interviewer: Is there anything else that is very difficult for you with regard to HIV/AIDS patients?) Unless the families have a problem, sometimes they do not want them to come into their homes and treat that person." LP4

> "What worried her a lot was that she couldn't attend the funeral because the family seemed to be very jealous of her closeness to X, so she did not attend the funeral though she wanted to." HP2

The following quote highlights how a carer provided assistance to children coming to terms with their parent's illness or helping them come to terms with the loss of a parent:

> "...the patients passed away and what worried me most was the patients children because when the patients passed away, they would come here and ask about their mother...I would sit with them and try to explain to them what happens a person is dead." LP2

The carer in the following illustration attempts to help families resolve conflict before the passing of the patient:

> "During the last stages of the patient, I try to bring the family (together) and talk to the patient and some of them have problems with their families, so I try to bring the family together and the patient and they could make peace before the patients passes on." HP2

Consistent with previous literature (Michele & Schneider; 2000; Swartz & Gibson, 2001), the very nature of home-based care for these participants requires a more intimate involvement with recipients; bathing them, feeding them, addressing basic needs, and in general becoming "part of the family"; this impedes the sustainability of any potential boundaries that may be formed between carer and patient. Unlike Bindell's (1991, cited in Swartz & Gibson, 2001) findings, the role ambiguity inherent in this work was consistent across both groups, suggesting that in this context role ambiguity was not associated with burnout per se. Carers from both groups extend themselves beyond what is required of them, displaying an inherent commitment and sense of loyalty to their community. This deeply rooted sense of commitment is in keeping with the notion of "ubuntu", a more collective consciousness, where the focus is on the greater good (Owusu-Bempah & Howitt, 2000). This greater good is embodied in the family, clan and community, in which cooperation and collective decision-making are emphasised (Meyer, Moore & Viljoen, 1997 cited in Naidoo, Shabalala & Bawa, 2003). This notion is at odds with individualistic Western constructions, where the focus is on the individual as an independent self-sustaining entity where the "attainment of a fulfilled self is practically synonymous with individual autonomy" (Owusu-Bempah & Howitt, 2000,

p. 7). Holdstock quoting Ogbonnaya describes the African concept of individuality as an entity that "emerges and expresses itself communally" (Ogbonnaya, 1994, cited in Holdstock, 2000, p. 104). Thus, cultural constructions of the self in relation to the collective influences the way carers interact with their community, and their coping in this context. Thus role ambiguity may not necessarily be experienced as stressful and damaging for these participants. Arguably participants may need to hold on to the belief that they make a difference in others lives, on many different levels, in order to continue working with PWAs, which may account for the high personal accomplishment scores in both groups.

Community and Family Stigmatisation

A shared experience amongst CHWs of HIV/AIDS patients was the stigmatisation encountered by PWAs, which impacted negatively on the provision of care in several ways. Firstly, HIV positive individuals were less likely to approach CHWs, fearing that CHWs may disclose their status to the community or family. In response to this, carers repeatedly asserted the importance of confidentiality. A carer describing this occurrence stated:

> "In most cases like in the townships, people consider HIV as a stigma, and if you have HIV, its like you have been sleeping around, or you like a prostitute…They think that the carers are going to spread the news about the HIV status and they don't trust them…" LP4

The following illustration highlights the implication of community stigmatisation on patient's willingness to disclose their status and cooperate with the carer:

> "…you know what to expect, and you know the patients status, but when you get there and try to talk to the person , to disclose about his or her status, it becomes very, very difficult, so you have to sit there and it takes a lot of time for the patient to open up." LP3

CHWs are caught in the uncomfortable position of maintaining confidentiality while the patient's health deteriorates. One CHW described walking a fine line between maintaining confidentiality in order to prevent potential stigmatisation while simultaneously trying to access the family's support:

> "…when you get to the home and the husband is sick and bed ridden and the wife does not know what the person is suffering from, so I can try and find out from the wife if she knows that the husband is HIV positive…and I'm trying to get the husband to disclose…if the husband discloses in the presence of the wife, than its very stressful because the wife did not know and she is shocked and in disbelief." HP5

Another carer expressed her concerns about confidentiality and community stigmatisation alluding to the implications for care in the home:

> "…at home the HIV positive are not accepted, and in the community, they get stigmatised and like (with) their families, (you) would find that they, they not keeping it private and tell other people in the community and sometimes people are not taken care of in terms of their nutrition…" LP6

Secondly, stigmatisation by the family leads to the neglect of PWAs; consequently CHWs become solely responsible for the care of the patient. This was a particularly stressful experience for participants from both groups:

> "…it becomes worse when the person can't eat, you have to be patient and feed them, you can't be harsh because there is nothing they can do about their situation…Its like some patients are not treated well at home, so its better for the patient when the carer is there, so when you leave you just think what's going to happen when you're not there, because the next day they tell you about their experiences, their treatment by their families, so its not nice for them to hear those words." HP4

> "The most difficult thing is the communities attitude towards HIV positive people, even the families, you see that they don't accept the person and our communities are not well informed by (about) HIV and AIDS. (Interviewer: How does that make your work difficult?) I had an HIV positive and the patient did not disclose to the family that he is HIV positive, and when I am there I would see that the patient is not comfortable because he has not disclosed to the family. Even after the patient passed away the family was curious and wanted to know why the patient was comfortable with the carer than with them…what makes it difficult is when there is no cooperation between the carer and the family." LP2

> "What stresses me the most, is to see the person at that stage, when that person is unable to do anything for him/herself, like the person "pees"(urinates) and soils and you know (you) can't do anything and the fact that they don't have anything to eat. And the family have rejected them, that stresses her a lot because the patient becomes dependent on the carer." HP3

These illustrations are characterised by patients' absolute dependence on caregivers, when family were unwilling to accept patients' status or where patients guarded their diagnosis for fear of potential rejection by the family.

Finally, CHWs felt that because the community were uninformed, HIV/AIDS sufferers received contradictory messages about HIV/AIDS:

> "… So when you get to that person, you can see that that person has lost hope…and the other thing is the community, the community's attitude to HIV positive people. So you pass on information as a carer and the people in the community, they are passing all the different messages, also there is some confusion there, so you tell the person that they are going to live longer, if you get medication nutrition or whatever, but the community sends other messages." HP6

> "Another problem is the family members or someone who cares for the patient at home, so when you get there as a carer you find difficulties, because you giving your own messages and own treatment, but they get different messages from the family members, because they are not trained, they do not know much about his disease." LP3

The community and family unit are not separate; their entwined relationship poses numerous challenges for both the High and Low Burnout groups. As illustrated, carers in this context are either avoided by patients or become their only source of support; in both cases carers experience considerable stress. While previous studies have concluded that negative social attitudes towards carers lead to an increase in burnout (Bennet et al., 1994), this was not applicable for the current sample. CHWs appeared to be more affected by the impact stigmatisation had on the quality of work they could offer to patients, and did not report being personally affected or stigmatised by the community.

Working in Adverse Conditions

Carers felt that the prevailing socio-economic context posed the greatest challenge to caring for PWAs. The difficulty most frequently encountered and reported was the treatment of patients who were malnourished. The majority of carers responded to this challenge by purchasing food items for patients at their own expense. This appeared to cause significant distress for participants who themselves, struggled financially, however this was consistently encountered by both groups:

> "The hardest part for the carers is the lack of resources and some of the patients, they are discharged from hospital and they must stay at home, so when you visit them you find that they don't have anything and than you have to take out money and buy some food for them." LP1

> "…the most difficult part is when you go to poor families and you can see that they have nothing, nothing, nothing, and then you feel sorry for them and you take money out of your pocket and help them. (Interviewer: Do you do this often, where you take out money for people?) I do that often, because with my other TB (Tuberculosis) patient, she used to come to me and say that she does not have anything and than I was forced to provide from my money and my food." LP2

> "I will cope better if we could get enough materials to work with, sometimes you find that there is no one working and people, they don't have food, so even if you give the treatment, you find that the patient is not willing to take treatment and is not cooperating because they are hungry."LP3
>
> **(High EE participants encountered similar difficulties; quotes in this regard have been noted in previous and subsequent themes)**

Furthermore due to the lack of transport, carers conducted home visits on foot and often transported patients to clinics using wheelchairs, illustrated in the following quotes:

> "...so now its winter, its raining, I must check my gumboots, or get a comfortable shoe because we walk long distances, the houses are far apart so you have to walk long distances and its cold, its wet." HP1
>
> " I feel that we need transport, to transport our patients, because we had one wheel chair, now we have two, but the wheelchair is not as fast as the transport." LP4
>
> "It's the walking distance and we are worried about our health and our shoes...Working with patients is not much of my concern but we are worried about the distances ...sometimes you spend two hours with one patient, so you might not get to all of them." HP4

In general, carers felt they lacked basic material resources to assist them in the care of their patients. One such resource frequently referred to were surgical gloves, which while available to some, were not available to others. The following accounts reflect anxiety regarding occupational exposure in the absence of adequate resources:

> "What makes it difficult for me, to deal with the HIV positive patients, because we have to bath them and feed them and the gloves that we are using are not strong and sometimes, people when they have bedsores, you bath them, you feel that the water has spilt in, so we sort of ensure that (if) we have a scratch we might get infected. (Interviewer: Is that a very big fear?). Yes, otherwise I don't have a problem with them." LP4
>
> "We do get gloves from the clinic but not everyday, sometimes we don't get it. (Interviewer: So when you washing the patient for example, do you always have gloves?) Yes, with the HIV positive. (Interviewer: Are you worried about being infected?) Yes. (Interviewer: Tell me more?) I could be infected if the person is bleeding, I might get contact with the blood...Its not happened before, but I'm aware of it...It worried me."LP3
>
> "Because the HIV positive patients are dying and that is very stressful and there is no cure for that. So the fact that there is no cure and people are dying is very stressful...It's the lack of equipment, And another thing is the safety and that's the fear of being infected. I am not sure, I am not sure how safe I am." HP5

While previous studies have asserted that fear of infection predisposes carers to burnout, it was not applicable to the current sample (Horsman and Sheeran, 1995). Fears of occupational exposure were consistent in both groups and were not associated with burnout. Nonetheless, CHWs in this context remain vulnerable to occupational exposure, given the lack of adequate safety equipment and/or resources.

The issue of social deprivation in relation to burnout has received little attention in the literature. While authors (Melnick, 2002; Michele & Schneider, 2000; Soal, 1997 & Uys, 2002) express concern about the practice of home-based care in substandard conditions, there does not appear to be an adequate body of research documenting the relationship between social deprivation, coping and burnout in CHWs.

"Not having the words"

This theme originates from responses to questions asked towards the end of each interview. Participants were asked what they needed to help them cope better with their work. In most cases, the immediate response was greater access to resources, such as shelters for PWAs, transport facilities and food parcels.

> "(Interviewer: What do you need, what more do you need to help you with this work?) As I've said before, I've got two disabled patients, when I get there I have to wash them and change them, I do not have enough materials, like the Kimbees. Sometimes you find that you have this piece (of) sheet and they are torn and they don't really help…I feel that I need more materials to help me." LP1

> "I feel that we need transport, to transport our patients…it's a problem, we do not have resources, the other thing is that we need a shelter for HIV positive patients so that they don't sit there at home alone, if they could come together and share their experiences." LP3

> "If there could be a day centre or special homes for these people, because they are left alone in their homes, they are not being cared for adequately, its like they are feeling lonely and thinking a lot, that's what makes them worse. Or they end up dying because they are lonely, there is no support and they could be a home or day care centre, where the carers can do their work." LP6

> "(What do you need to help you cope? *Carer paused for a long time, the question was repeated twice, the carer appeared confused and continued to remain silent after repetitions, eventually responding*) I'm building a house, with

> the walls only, so if I could finish the house and have a place where I could spend time with the clients, that would make me feel better." HP2
>
> "If we could get a shelter for the patients that would make our work easier." HP4
>
> " I wish that there could be a shelter here in Khayelitsha..." HP5

Due to the potentially emotionally distressing nature of the work, the follow up to the preceding question was an inquiry into what participants required emotionally/psychologically to help them cope better with their work. While a small proportion of carers indicated that they were satisfied with the support they received, the majority struggled to articulate their emotional needs. Difficulty with this line of questioning was evidenced by long pauses, and requests to repeat the question. In general, CHWs equated emotional support with more tangible forms of support, this being monetary incentives, medical aid, and shelter's for PWAs and additional material support:

> "(Interviewer: What about emotional support?) There are something's, like if you need support, some incentives, to get an incentive, to get an increase." LP2
>
> "(Interviewer: And in terms of emotionally, what do you need to cope? *Participant responds in English*). There are many. What we really need is money, because we can't support our families and we have children in school, if the government could get involved and help the carers. (The emotional part, is that difficult?) I can't say it's the medication, emotionally I'm drained and stressed. (Translator: Is it difficult to express?) *Participant reverts to responding in Xhosa.*" HP1
>
> "(Interviewer:...do you feel you get enough emotional support from everyone?) No not enough. (Interviewer: Could you tell me a little more about that, what more support would you like?). I want support from the Caring Network, for instance when we are sick, we don't know how we are going to get to the hospital and how we are going to pay because we have no money." HP4
>
> "I would like more support from the Caring Network, but they do support us, but not emotionally, but with medication and other stuff. (What type of emotional support do you require?) The question is difficult, because I've mentioned the money, the shelter, but about the emotional support, that is very difficult. (Interviewer: Why?)...Participant could not answer and goes on to say...very little transport and I wish that the HIV positive patients could get some medication and get cured with their illness. (Interviewer: I'm noticing that you are not talking about the emotions at all, is it very hard to talk about feelings). Its difficult and I need to think about it." HP5

The next carer felt unsupported by the organisation, but believed that time off from work was one way she could be supported emotionally:

> "I don't have support from the organisation. (Interviewer: What would you like them to do?) If we could have, because sometimes we get stressed out, so we need some time to relax, if we could get some time off to relax." LP3

Words like "felt sad/saddened", "happy", "aggrieved", "hurt", "angry" and "cross" appeared to constitute the sum total of carers dialogue in describing their emotional states. Drennan (1998, p. 23) asserts that, "…there is enormous variation in the emotional states for which any particular language has a word. In the English language there are 1500 single words that describe emotions. But although other cultures have fewer words, this does not imply that their range of emotional expression is less broad or deep." What appeared to be the lack of an "emotional language" may instead reflect the researcher's positioning within a Western psychological discourse, where experiences are psychologised, creating assumptions and expectations that participants engage more "meaningfully" with their emotional experiences and needs.

An alternative interpretation of the seeming lack of emotional verbalisation in the sample is that emotional distress may be expressed in more than just a verbal modality. While not a predominant feature, participants from both groups intermittently expressed their emotional distress through physical symptoms:

> "…but when the person is very sick and weak, I also feel weak, but I tell myself, I must be strong." LP4
>
> "I was very sad, because it was the first time to see a dead person. I was not well and fell sick for a few days after that…I felt my head was numb, was shaking and trembling sometimes and feeling very hot." LP6
>
> "Its not that I do not like the job, or I'm is working herself up…I'm not sure whether I'm stressing or what is going on, but sometimes I feel physically not strong…sometimes its headaches, its back pains and I just take the tablets, sometimes the headache goes away." HP1
>
> "Headaches and muscle tension, maybe I do not take notice of others, but mainly it's the headache and tension." HP6

While this may not be applicable to all participants, it introduces the idea that participants communicate distress in other ways, and somatising may be one such form, for which there have been opposing views. Somatization has been the most commonly quoted feature of depression in Africa (Drennan, 1998). However, a cross-cultural study conducted in eleven countries revealed that as a presenting problem, somatic complaints were no more frequently seen in developing countries than in other contexts (Gater et al., 1991, cited in Swartz, 1998). Researchers examining differences in levels of somatic and psychological symptoms have viewed such differences in terms of the evolution of those societies (Kleinman & Good, 1985; Swartz, 1998). In contrast, Klienman (1995b, cited in Swartz, 1998) does not view distress as a primarily psychological process transformed into a somatic complaint, and suggests that somatization may be the manner in which social interactions are conducted and/or assistance is elicited.

Alternatively, not having the words may involve the inhibition of emotional expression, a coping style termed self-controlling, which was found in one study to have predisposed nurses to burnout (Celowitz, 1989, cited in Duquette et al., 1994). The avoidance of expressing emotional needs may reflect a coping style, allowing CHWs to continue working in the face of overwhelming social deprivation. However the notion of "self-controlling" itself, is a Western construct and may not be entirely applicable in this context. Furthermore, participants across both groups were unable to express their emotional needs; thus self-controlling did not appear to be related to burnout.

An additional, yet salient feature worth considering was whether participant's perception of the researcher prevented them from providing more detailed accounts of their emotional needs. Participants had previously participated in research sanctioned by the organisation, in which they had expressed their grievances and what they required from the organisation to help them better manage their work. Subsequently, according to one participant, members from the organisation approached the group and allegedly confronted them on results obtained from the evaluation. The participant felt that this fostered strained relations between the carers and the organisation. While this was an isolated response, it suggests some consideration of participant's perception of the researcher: given his ongoing interaction with trainers and having access to participants through the organisation, which may have made participants reluctant to express their feelings more openly.

4.2.2. Differences between the High and Low Burnout Groups

Number of Patients

CHWs from both groups work in conditions of extreme deprivation, confronting similar challenges. However, a stark contrast between the groups was the average number of HIV/AIDS patients being treated at the time. High Burnout participants managed a larger caseload of diagnosed HIV/AIDS patients and had experienced more recent patient deaths than their Low Burnout counterparts.

On average, participants in the High Burnout group managed two or more diagnosed[1] HIV/AIDS patients with a maximum of eight. With the exception of one participant, members of the Low Burnout group managed no more than two diagnosed HIV/AIDS patients. Consequently, members of the Low Burnout group had greater variation in the patients they treated, in marked contrast to, for example, one High Burnout participant who had never been exposed to anything other than HIV/AIDS care. Fifty percent of the High Burnout participants had recently lost patients; few recent losses were reported amongst the Low Burnout group.

The finding that CHWs experiencing greater emotional exhaustion and depersonalisation, manage more HIV/AIDS caseloads is consistent with previous observations that spending sixty per cent of the working week exposed to PWAs was not only the threshold for avoiding psychological distress,

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[1] Carers distinguished diagnosed HIV/AIDS patients from TB patients, who in some cases were HIV positive and in other cases had not been tested. For the purposes of this study, only patients that carers had identified as HIV positive have been referred to.

but also a potential risk factor for burnout (McKusick & Horstman, 1986 & Miller, 1988 cited in Catalan et al., 1995).

Emotion- Focussed Versus Problem-Focussed Coping

Differences in coping between the groups became apparent when each participant was asked to reflect on a recent stressful event in their work. Further exploratory questioning in this regard elicited the various coping mechanisms utilised in these situations.

Stressful situations amongst High Burnout participants frequently involved young children of the patient, starving families, occupational exposure and patients that recently passed away. Carers were particularly distressed when young children were involved. In this context, they were usually responsible for feeding children or helping them come to terms with the inevitable loss of a parent. Participants of this group, unlike their counterparts, more frequently utilised emotion-focussed strategies of escape-avoidance and denial in response to such stressors. The following illustration depicts the participant's coping response to a stressful encounter:

> "What stressed me out a lot, is the patient, I have just taken to the clinic, she is a married woman and they have a small child, what stresses me a lot is the child, the mother seems to be in not good health, but she is not that weak…Last year November the patient was very serious and could not walk or could not get our of bed and the child was always around demanding attention, and the mother would tell the child that that her (the mother) future was short, so that stressed me a lot because the child could not understand what was going on with the mother…(I told her) to accept her condition, to pray harder and if she prays harder, she's going to, and try to be strong and she must think of the child, who is going to take care of the child when she is gone." HP2

The participant in the preceding example appears to have utilised religion as an emotion-focussed approach in addressing the problem. It is uncertain whether this tactic addressed, or exacerbated, the problem; when asked how this resolved the stressor, the participant was unable explain how it helped the child. To some extent, the participant employs denial of facts as a way of coping, the factual component being the child's distress (Janis, 1958 cited in Lazarus & Folkman, 1984). At no point does the participant address the child, but invests her hopes of change in prayer, arguably denying the reality and multiple complexities of the situation.

While the fear of occupational exposure was a shared concern, the following examples highlight how the High Burnout participants reconcile the reality of potentially being infected:

> "…I told myself that this is a job and I have to do, but if it happens it happens." HP4

> "I feel that I carry this with me, I put myself in that situation and I'm also married and I think about the situation as a married woman, when you don't know that your husband is HIV positive. *Later in the interview* (Interviewer: What do you feel inside?) I don't feel happy, I feel sad. (Interviewer: But what do you do with that, how do you deal with those feelings?) I just tell myself that this could happen to anyone." HP5

While these somewhat careless comments may allow the carer to continue working with PWAs, it also reflects denial of the severe consequences of occupational exposure and implications thereof (Janis, 1958, cited in Lazarus & Folkman, 1984).

The participant in the following example highlights how she avoids thinking about the inevitable death of a patient; the following example highlights the impact of such denial:

> "I don't really focus on the idea that the person is not going to get better or the person is going to die, because I think that that will affect me emotionally…death is death and anyone could die, so it's the same…and I have to come back the next day and if I have to give the person their medication and bath the person, so if I tell myself that today, I have done this…so maybe the person is going to die, so that is going to affect me emotionally. (*Later in the interview.* Interviewer: Think back to a recent case, a patient that passed away as a result of AIDS, how did you respond, how did you react to that when you found out that the person died?) The one patient died recently, but she was sick… and than she phoned the ambulance and called the Sisters…the person died a few days later…nothing happened to me after I phoned the nurses and the patient was taken away, but I was informed a few days later that the person had died. That's when I referred back and realised that I could see that the person was going to die." HP1

In this instance coping by denying a patient's inevitable death seemed to have impacted on the carer's ability to notice that the patient was on the verge of death. Furthermore, this is consistent with Janis' (1958, cited in Lazarus and Folkman, 1984) assertion, that denial may lead to momentary ease of distress but leaves the individual vulnerable to stressors on subsequent occasions.

Avoidance was also used as a coping mechanism in other settings. The participant from the preceding example recalled how distressing it was to be exposed to patients with full-blown AIDS:

> "Its more when the patient is in their last stages, so when the patient sees her coming, there is that hope that they are going to get better…whereas she can see that the patient is not going to make it, so it is better for her to stay away because she does not want to delay the patients death. (Interviewer: But does that also help you cope?) It helps me, because I feel that I am delaying the death by being present when the person wants to die." HP2

The participant copes with this potentially traumatic encounter by simply avoiding it, reflecting her struggle with issues of death and dying. The use of escape-avoidance has been associated with all three symptoms of burnout in previous studies (Thornton, 1991).

The High Burnout group's higher depersonalisation scores may either be the consequence of these coping strategies, or a coping mechanism in itself. As a coping mechanism depersonalisation can act as a form of denial, where carers deny the multifaceted nature of the individual patient's problems by objectifying them. However, it is worth mentioning that while this may be the expected consequence of burnout, there was no evidence in the text to suggest the onset of negative, cynical attitudes towards clients, characteristic of depersonalisation.

Similar to the High Burnout group, stressors for the Low Burnout group were predominantly characterised by the loss of patients and helping children come to terms with the loss of parents. While these carers utilised a range of different responses to situations, their style of coping was predominantly problem-focussed with the flexible inclusion of emotion-focussed coping where applicable, which was generally more adaptive to the context. In the following case a carer was confronted with two very ill siblings, both on the verge of death. Responding to the crises the carer states:

> "I was so saddened by this situation and didn't know what to do about it and there was a family there and I did not know…what to say to the family. Because of the situation I asked the family if they could pray first, and they prayed and after praying I asked the family to relieve me for a moment. After the

> praying I went away and spoke to someone in the community for advice…so they took the daughter to hospital." LP1

In this example the carer uses prayer as an emotion focussed approach but in addition utilised a problem-focussed strategy by seeking out advice. Another carer felt unappreciated by the sister of a patient. She recalled having a particularly stressful interaction with the sister, which she coped with by drawing on a repertoire of coping resources that were both emotion and problem-focussed:

> "When I got home, what made me feel better, I rested a bit although I was thinking about the situation, because I like gospel music, I played gospel music, to relax in my mind…the feelings did not go away at the time, it took some time, it took some time to get over it…I also talk ed about it with my colleagues, talked about it, over and over again and I felt better." LP3

Here the carer, on realising that simply resting would not alleviate her distress, sought out other sources of comfort. She appeared to employ mental disengagement as a coping technique in this context. Carver et al. (1989) argue that under certain conditions this coping style may be adaptive but that such a response often impedes functioning. It is evident that this participant was able to recognise the limits of such a coping mechanism as she actively sought out social support. Talking about the problem "over and over again" seemed to have given her the opportunity to adequately process and digest the unpleasant experience.

The following excerpt highlights a participant's multifaceted use of social support, in addressing a stressful situation:

> "I feel cross sometimes. We feel sad, but sometimes, you just feel like you can't do anything, you can't take away the pain from the person. (Interviewer: But what about your pain?)…I come back to the group and talk to them and tell them how I feel and get advice and support from the group. (Interviewer: And how does that help?) It helps me a great deal and the counselling staff provides some support and counselling. (Interviewer: Do you have a counselling staff?) Those in the group, those who have done it." LP6

The participant recognises that the group can serve numerous functions, she accesses these sources of support, for emotional reasons, and by utilising the support, pragmatically, by getting advice, taking it a step further by accessing trained counsellors in the group, for more specialised forms of support.

It therefore appeared that Low Burnout participants drew on a wider variety of coping resources than High Burnout participants.

Use of Social Support

Both groups drew on social support as a coping resource. However for the High Burnout participants, social support was more often accessed as an emotion-focussed approach to coping, while Low Burnout participants utilised social support more flexibly, accessing both its problem and emotion-focussed resources.

The majority of High Burnout participants admitted to accessing social support from family members, social workers, church groups, colleagues, hospital Sisters and supervisors. For the most part however, social support was a source of emotion-focussed coping:

> "What helps me is talking about the problems and her difficulties and I have contact with social workers and other people, so I am open, I am talking about my problems, and I feel better when I have spoken about my problems and some people can learn from my experience. I am relieved and the next thing I feel I can do it again." HP1
>
> "I feel better talking about it and crying…that's how I normally deal with it. What helps me, is to talk about my problem, I find that it is very hurting to keep it inside me, so I share with other co-workers." HP3
>
> "It gets better when we share with the group, and we tell each other that we can see that the person is dying, so we also pray that God must take the person away because they are suffering." HP4.

Carver et al. (1989) drew a distinction between seeking out support for instrumental reasons (problem-focussed coping) and for emotional reasons (emotion-focussed coping). Participants accounts of "talking to people" and feeling "relieved" as a result, denotes a more emotion-focussed style of coping.

In contrast the Low Burnout participants utilised social support more frequently; its use as either an emotion-focussed or problem-focussed resource was dictated by the prevailing context:

> "(Interviewer: When you have problems like this, do you normally talk to your colleagues?) I find that some of them have similar problems like I did. (Interviewer: when you talk, how does that help you?) When I have talked about the problem, I find that my co-workers give me some advice and sometimes I find that I am not the only one experiencing this problem. (Interviewer: Do you talk to them about your feelings when you talk to them about your problem, about the type of feelings you had as a result of what happened, or did you just get practical advice and does that help you?) We talk about our feelings." LP3

> "(Interviewer: How do you get over your pain?) When we come back from home visits, we come here as a group and share our problems, so we support each other and equip each other with information on how to deal with that particular problem." LP5

> "(Interviewer: How did you deal with these feelings during this stressful time?) I come back to the group and talk to them and tell them how I feel and get advice and support from the group." LP6

The following excerpt illustrates how a participant derived affirmation and emotional support from the group in response to a stressful encounter.

> "I was very sad and hurting and I always shared with the group…the group supported me and told me I was doing the right thing…What we normally do as a group when we come back from our home visits, we share our experiences with he group as we always work together, it helps talking about it, because you deal with the problem and you talk about it openly and it helps to get it out. I also talk to the church group, the women's group." LP2

The participant in the next illustration speaks of accessing support from the group after the death of a patient.

> "When we are sharing our problems, some of us encourage us, when we share with the group, we feel some relief." HP4

The act of "advice giving" and "equipping" each other with information reflects Carver et al's. (1989) instrumental use of social support. Furthermore, being affirmed by fellow group members constitutes an emotion-focussed approach to coping. Unlike High Burnout participants, the Low Burnout group utilised a more variable form of social support. Thus, while social support was available to both groups, High Burnout participant's accessed it more frequently as an emotion-focussed approach, while the Low Burnout group used social support both pragmatically and for its emotional benefits. The findings amongst the Low Burnout group are consistent with findings from previous studies, i.e. that social support is a valuable resource for coping and alleviating the risk of burnout; however these studies did not distinguish accessing social support for its problem and emotion-focussed resources, instead focussing more on the quality of social support received and the implications thereof (Bennet et al., 1994; Duquette et al., 1994; Jansen et al., 1996; Maslach, 1982; Miller, 2000; Munley, 1985; Ogus, 1992). Thus the present findings suggest that social support may be most effective if utilised both instrumentally and emotionally.

Passivity Versus Agency

High Burnout participants turned more frequently to religion as a way of coping than the Low Burnout group. Both groups were questioned on what strengths they drew on, when confronted with situations where little could be done. High Burnout participants appeared to lack a sense of agency, more often turning to a higher power beyond themselves in response to situations where little could be done.

> "(Interviewer: When you go to a home and when you see an HIV patient, and they are starving and not coping, you do as much as you can, you've done everything and there is nothing more. How do you deal with that, how do you find peace in yourself?)…working with HIV positive people, sometimes you feel like you don't have anything, but if you could have faith in God and pray, you feel better, even though you don't have anything to give them, or you've given up hope, so when you pray and have faith in God, you know that God is going to help the family, so you going to feel better." HP1
>
> "(Interviewer: What about a situation where there is nothing more you can do, how do you deal with that, what do you tell yourself?) I pray for the person and accept that the person is going, I must let the person go…the prayer helps me a lot, it gives me strength and now that I have cried a lot, I am going to feel better." HP4
>
> "(Interviewer: People say the work you do as a home based carer is very difficult, and when things get very difficult how do you carry on?) I pray a lot…It helps me because when I pray I feel that I am okay and strong." HP5
>
> "(Interviewer: What happens when the work becomes too difficult, how do you carry on, what strength do you draw on to carry on?) Maybe my belief and faith in God, I am a believer…(Interviewer: How do you keep the hope alive?) About the patient or about myself…The Bible…maybe it's that belief that these things were meant to happen to us as human beings." HP6

Thus, when confronted with situations where little could be done, participants managed their helplessness by turning to religion, to either reframe or reinterpret the experience, or to draw strength from prayer. Coping in this manner may not adequately alleviate emotional distress and may have predisposed these carers to burnout. The chronic nature of stressors and ongoing deterioration in patients' health remain constant features of home-based care; as such turning to religion in the absence of supplementary problem-focussed strategies is not adequate or functional in this context. However, problem-focussed strategies may not be useful if the situation itself cannot be altered, as is the case with terminally ill HIV/AIDS patients. Thus participants with high HIV/AIDS caseloads (which characterise the high burnout group) may adopt religion as an emotion-focussed coping strategy as problem-solving strategies are less likely to be effective.

While reference was made to religion amongst Low Burnout participants, it was not the predominant focus amongst the majority of these carers. As a coping mechanism, religion was usually utilised in combination with a series of other coping strategies. This has already been illustrated in the preceding section on stressors, referring to LP1 who combined problem and emotion-focussed approaches in dealing with the stressor, through the use of prayer and obtaining additional advice. In a similar vein, the following illustration depicts a CHWs use of religion in conjunction with social support; here the participant actively seeks out the support of her church group:

> "I also talk to the church group, the women's group, the people I trust." LP2

There were marked differences in responses to similar questions posed to the Low Burnout participants. While High Burnout participants passively coped in situations where little could be done, Low Burnout participants offered different responses:

> "(Interviewer: And tell me, they say that this work that you doing is very difficult…when things get very difficult what helps you carry on?). It has not been that hard, very hard for me, I mean doing this kind of work, to the extent that I just give up and leave it, and I think that its because its like a calling for me to make a difference in other peoples lives and care for other people…sometimes its get harder, but because I like this type of work, I just carry on. (Interviewer: And when it gets harder, do you tell yourself that this is your calling and this is why you here?) *Participant enthusiastically shouts* Yes!" LP1

> "(Interviewer: People say that this work is difficult, when it feels like its very difficult, how do you carry on?) What keeps me going is that I like my job. (Interviewer: What happens when you've done

> everything you can do and can't do anything more, how do you carry on then, how do you cope with that?) I have never had that experience, of feeling like I've done enough, feeling helpless…" LP2
>
> "The nature of this work is very, very difficult, but for me even though it is difficult, I haven't been confronted with very difficult situations to an extent that I would give up." LP3
>
> "It has not been very difficult in terms of the work, I do. (Interviewer: When you faced with a situation where you've done everything you can do and where there is nothing more you can do to help the patient you care caring for, how do you deal with that?) Its not easy for me to give up and I do not show the patients that I am loosing hope, although I know that I have tried my best and tried every effort, even if I can see that there is nothing I can do, this is beyond my capabilities, I will just carry on and do the work I am supposed to." LP4
>
> "There has never been a time when I felt like I cannot carry on with the work, the Caring Network will take us out because of the kind of work we are doing, whether you are coping or not coping…(Interviewer: What happens in situations where there is nothing you can do…?) Because the person has his or her time to die, so you just tell yourself, console yourself, by telling yourself, I've done my best and so there was nothing else I could do if the person dies." LP5

Low Burnout participants appeared less discouraged in their work. When confronted with similar situations in relation to their High Burnout counterparts, Low Burnout participants appeared more positive with a stronger sense of agency. These findings are consistent with the notion of control as a feature of personality hardiness, which previous studies have concluded was negatively related to burnout (Duquette et al., 1994; Jansen et al., 1996; Topf, 1989). While this may reflect a more adaptive approach to coping, it is also possible that Low Burnout participants were exposed to a context that lent itself to a wider variety of coping resources: Carers from the Low Burnout group were exposed to illnesses other than HIV/AIDS, so while they confronted similar situations to the High Burnout group, they did so less frequently, maintaining a greater sense of control with regard to their work. The findings suggest that a stronger sense of agency could be attributed to personality factors, and/or to job factors (HIV/AIDS caseloads); the two may interact and influence the manner in which CHWs cope, determining their predisposition to burnout.

Acknowledging Limitations

As shown previously, when confronted with malnourished patients, some carers addressed the situation by purchasing food items at their expense. Managing larger HIV/AIDS caseloads meant that carers in the High Burnout group encountered and responded to such difficulties more frequently. As shown previously one participant reported utilising a problem-focussed approach by purchasing food items on credit for patients when she lacked financial resources.

> "The most stressful thing is the patient I was talking about, the one who has children and a one year old. When she goes there she has to think about what she is going to bring (take), you know, what she is going to put on the table…it has become unbearable because I have to cough up from my own pocket. This is a list of the stuff, I have bought for the patient, item and payment. (Carer opens a book and shows us the list)." HP1

The interviewer goes on to explore how the carer reconciles the impact of addressing problems in this way; the participant responded by saying:

> "Sometimes I do not feel happy about this whole thing and feel saddened, but at times I tell myself that I am just in it, I have sold myself, I'm in it. I can't drop now, but sometimes I feel like I am at the end of my rope, but because I want to help people, I just carry on although it hurts me." HP1

Problem-focussed coping in this context is maladaptive as it further predisposes the carer to burnout. In addition, the carer's justification of having "sold herself" or "I am just in it" reflects a reinterpretation of the situation, however this emotion-focussed approach does not appear to alleviate the distress experienced. These responses also reflect denial of the complex reality of home-based care as well as its implications for the carer.

Being unable to identify the limitations of their work, carers were unable to separate themselves from their work:

> "…Its like some patients are not treated well at home, so its better for the patients when the carer is there, so when you leave, you just think that what's going to happen when you are not there , because the next day they tell you about experiences…ts very difficult, I can't separate that, because even over the weekend, if I left a patient not feeling good, I'm going to carry that with me." HP4

> "Maybe if I can separate myself from the patients situation." HP6

Like their High Burnout counterparts, Low Burnout participants also confronted the challenges of social deprivation but appeared more able to acknowledge their limitations:

> "The most stressful thing is when you go to their home and you find that the family is poor and there is nothing to eat, and our work has limitations and you feel that now you have to stop here and the family has to take care of the patient…sometimes I feel frustrated if there are limitations, the supervisors will tell them that they do not have to do this, because it is the family matter, and you don't have to do this because it is for the social workers…" LP4

The participant in this example reframes and reinterprets the event acknowledging the limits of what she can achieve. The following quotes are participant's reflections on the harsh realities of their work and limitations in this regard:

> "I feel sad sometimes, but you know that this is your work and you have to do it…(Interviewer: …what do you tell yourself when you work with these people, how do you deal with that, knowing that this person is never going to get better?) I tell myself, I have done my work, I help the person even though the person is not going to make it, I just tell myself that I have just enough." LP2

> "Because the person has his or her time to die, so you just tell yourself, console yourself, by telling yourself, I've done my best and so there was nothing else I could do if the person dies." LP5

> "I feel cross sometimes, I feel sad, but sometimes, you just feel like you can't do anything, you can't take away the pain from the person" LP6

These participants reinterpret the situation and continue to help the person, while acknowledging their limitations. Perhaps coming to terms with the reality that the "person has his or her time to die" and that emotional pain, for both the patient and carer, is an intrinsic part of the work, helps the carer recognise what can and cannot be changed. Although all CHWs go beyond their official job descriptions, unlike the High Burnout group, the Low Burnout group seem more able to acknowledge boundaries and separate emotionally from their patients.

Processing the Experience of Loss

Coping styles were also elicited through questioning about carers reactions to the death of patients. High Burnout participants experiences in relation to loss were more often characterised by feeling unappreciated, coping by distracting oneself with new cases, and losses that were fairly recent, and as such had not been fully integrated and processed.

The sense of being unappreciated had a profound effect on carers; this was exacerbated by carers' over identification with patients and their role ambiguity. The following participant reflected on the death of a patient in the previous year, throughout the interview she frequently over identified with patients and equated them to her own family. She remained vague in her account of the experience but on further questioning admitted that it was the lack of appreciation from the extended family that hurt her the most:

> "The reason I am able to work with HIV positive people, I am thinking about my own children, because you never know what might happen…it could be my child the other day…*Later in the interview*…I went to the funeral, but when they (extended family) were going to the cemetery there was no space for me. Like it was, "we are the family and who are you?" HP2

In a similar vein, another participant lacking recognition, recalled an incident where a patient passed away shortly after she had visited:

> "The patient died after I had visited her and I was told that the patient had passed away and I wished that I was there and maybe the patient would have said something, to thank me for caring." HP5

In both instances the experience of feeling unappreciated or not recognised had a negative impact on carer's experience of loss and how they processed and coped with the event. In addition, feeling unappreciated may create feelings of depersonalisation; alternatively a sense of depersonalisation may lead CHW's to feel perpetually unappreciated.

Participants in this group also reported that the high turnover of cases allowed them to shift their focus from loss, to the management of a new case. This form of mental disengagement served to distract the carers, however it also prevented them from adequately processing the experience of losing a patient:

> "Maybe it's the feeling that you tell yourself that the person is gone is gone, so you get the next one, so that's what keeps me going, you get the next person and you have to care for the next person, so you just carry on and carry on." HP6

> "Because as carers we are not dealing with one or two people…so you have this case and the person passes on, I mean you get hurt, but in two days, three days there is something else, you focus on that one now." HP1

This inadequate processing was further validated by a participant's response to the interview:

> "I feel that now that you are talking about it, I thought those feelings were gone, but now that we are talking about it, I feel that they are coming back…I realised that this has brought up some feelings that I have been trying to suppress and neglecting them as if they are not happening." HP6

While issues of death and dying were equally distressing for Low Burnout participants, unlike High Burnout participants, members of the Low Burnout group had not experienced any recent losses at the time of the study. Asked to reflect on previous losses, their experiences were characterised differently: Participants derived a greater sense of appreciation from their work, partook in cultural practices and rituals more often than members of the High Burnout groups, and utilised social support and religion to help them cope with the losses.

A participant reports having previously lost two siblings a week apart from each other, when asked how she dealt with these losses she stated that:

> "I feel sad because as I'm doing these home visits, I get used to the patients, and you just regard them as your brothers and sisters and get used to them, so when they pass on, it sadden her a lot…What makes her feel better is when the person has died is to attend the night vigils, in our culture you take about one week to two weeks before the person is buried so you attend those evenings, those night vigils. And the fact that the family of the deceased appreciate what she has done for the deceased has helped her a lot, because they would announce in the meeting, "This is X, she has been helping us with this patient", basically its going to the night vigil, talking to the family and sharing all their experiences and being recognised and appreciated for the work she has done for the patient, that makes her feel better." LP1

The over identification and reference to patients as "brothers and sisters" seemed to have positive implications in this context. Being appreciated served as a powerful mediator of burnout. In addition cultural rituals provide a framework of mourning and help both carer and family process the loss of patients. These practices form part of an emotion-focussed coping style (Lazarus & Folkman, 1984).

While carers in this group appeared to utilise emotion-focussed coping mechanisms after the patient had passed way, it seemed that they also utilised a combination of problem and emotion-focussed coping prior to the patients passing, illustrated in the following examples:

> "(Interviewer: What if you are at a home and there is nothing you can do to help the person, what happens then…you've tried everything and you just can't do anything to take them out of their pain, what happens?) I talk with the person and we also use the memory boxes, I ask them, if there is something they want to put in their memory boxes, when I see they are in their last stages, so the family does not have to fight over their assets, if left behind…Its like if the person has a child, we ask them to write something and out it in a memory box…like whom she would like to take care of the child when the person is gone." LP6
>
> "I feel saddened by the situation…calling the ambulance is the last resort if you can't do anything more." LP1
>
> I help the person even though the person is not going to make it…." LP2
>
> Its not easy…even if she can see that there is nothing she can do, this is beyond her capabilities, she will carry on and do the work she is supposed to do." LP3

Coping with the experience of loss appears to be influenced not only by a coping style, but also by the context in which the loss occurs. The High Burnout group may have utilised less adaptive coping mechanisms, which may have been exacerbated by experiencing a greater number of losses, including recent losses. More recent losses may have elevated burnout scores, suggesting that the context of care may impact on one's predisposition to burnout at any given point in time.

Concluding Comments

The preceding themes highlight the different approaches to coping between participants from the High Burnout and Low Burnout group. Participants from the High Burnout group appeared to rely on a limited repertoire of emotion-focussed coping strategies; in contrast, Low Burnout participants displayed a wider variation in their coping repertoire with more flexible coping responses. However, a salient feature, and one that impacts on coping between the groups, was the varying contexts of care, with the High Burnout group confronting more death and PWAs than the Low Burnout group. In both groups, participants' approaches to coping may have been influenced by the work context and not only by internal coping resources.

4.3. Summary of Chapter

This chapter has provided an overview of both quantitative and qualitative findings, in which an attempt has been made to explain the quantitative findings through the qualitative analysis of participant's experience. Some experiences are shared amongst the High and Low Burnout groups, while others are distinct. Shared experiences include, "going beyond the call of duty", community and familial stigmatisation, working in adverse conditions, and "not having the words". The groups differed in their patient caseloads, their use of problem and emotion-focussed coping, and their use of social support. Additionally, a sense of passivity versus agency and different abilities to acknowledge limitations, also distinguished the two groups from each other. Finally, the different ways in which the two groups processed loss was highlighted. Salient to the overall discussion was the influence patient caseloads may have had on the choice of, and access to, coping resources.

CHAPTER FIVE

CONCLUSION, LIMITATIONS & RECOMMENDATIONS

5. Introduction

The following chapter details a discussion of the main conclusions and limitations of the present study. This will be followed by future recommendations for research and practice in the field of community health care for PWAs.

5.1. Conclusions

The High and Low Burnout group confronted similar challenges with regard to home-based care. Both groups experienced role ambiguity and a lack of resources, but these organisational factors alone did not seem to be associated with burnout. A high degree of involvement in their patients' lives may be in line with the cultural notions of community, and may have mitigated against high depersonalisation while enhancing a sense of personal accomplishment. Community and familial stigmatisation did not seem to be associated with burnout; arguably, the consequence of a predominant focus on the quality of work, with less of a personal focus. Consistent amongst both groups was an "inability" to verbalise emotional needs; it was unclear whether this was a coping style in response to overwhelming pressures, a manifestation of cultural differences between participants and researcher, or due to other factors.

The two groups differed in terms of the number of PWAs they treated, which may have influenced the context of care and coping resources that CHWs drew on and had access to. The High Burnout group predominantly utilised emotion-focussed approaches, resorting to religion and utilising denial and avoidance processes. This did not seem particularly adaptive, given their higher burnout scores. The Low Burnout group drew on a wider range of coping resources, perhaps being more available due to the variation of illnesses in their respective caseloads. The High Burnout group utilised social support in a more emotion-focussed manner, while the Low Burnout group accessed social support for both instrumental and emotional reasons. The High Burnout group lacked a sense of agency and more frequently turned to religion as a coping strategy; in contrast, the Low Burnout group had greater control over their work, accessing a wider array of coping resources. While this was attributed to personality hardiness in the Low Burnout group, the prevailing context was also considered, and how coping resources were more accessible, as a result. The High Burnout group struggled recognising inherent limitations of their work, while the Low Burnout Group seemed more able to acknowledge boundaries and separate emotionally from their work. Finally both groups differed in their approach to processing loss, although the High Burnout group utilised less adaptive coping strategies in relation to their Low Burnout counterparts, it was argued that their ability to cope was influenced by a greater number of losses, as well as more recent losses, which may have predisposed them to burnout.

5.2. Limitations

The present study was limited by its cross-sectional design. As illustrated in the thematic analysis, the changing contexts of care may have an influence on burnout scores and coping. As Payne (2001) indicated, a study of this nature can at best make inferences about possible relationships between variables at one point in time, limiting applicability to other contexts. In addition the sample size of 12 was fairly small and may not constitute a representative sample of CHWs providing home-based care. However, the study aims to be exploratory in nature, suggesting possible pathways for further research rather than attempting to characterise the experience of all CHWs.

The sample was drawn from varying geographic areas. Undoubtedly each geographical area may have its unique set of stressors, which would have implications for coping and burnout. The present study did not explore the influence geographical positioning had on participants coping styles. It is suggested that this be an area for future research.

While every attempt had been made to validate arguments, the researcher's positioning within a Western psychological framework formed the lens through which texts had been interpreted; this acknowledgment leaves room for other interpretations, which may be equally applicable.

Finally, the study was limited by its use of the MBI as a basis for allocating people to High and Low burnout groups; especially the Xhosa version administered in the present study, which has not been validated in the South African context and may not have adequately identified participants on high and low ends of the burnout continuum.

5.3. Recommendations

Findings of the present study suggest several recommendations for future research and practice in community health work with HIV/AIDS.

Firstly, there needs to be a more concerted effort to extend research beyond the confines of hospital settings and into the community, particularly in developing countries. In this regard, research on burnout and coping in the context of HIV/AIDS needs to expand its focus across cultures. This is particularly pertinent in the South African context, where black South Africans provide a large proportion of HIV/AIDS care. Thus, an understanding of their experience is central to the development of future programmes focussed on preventing and addressing burnout. In this regard, more research into "not having the words" should be conducted in order to establish whether this was a function of language and/or culture, or a coping strategy in the face of emotionally distressing work. If identified as a coping strategy, additional research needs to establish whether this exists as an adaptive or maladaptive coping style.

Secondly, participants predisposed to burnout seem to manage more HIV/AIDS patients than those not predisposed to burnout. It is recommended that community health care organisations maintain some degree of control with regard to the HIV/AIDS caseloads assigned to CHWs.

Thirdly, psychoeducational workshops on emotion-focussed and problem-focussed coping strategies may be helpful in further enhancing coping among CHWs. These should include input on acknowledging limitations and setting boundaries on one's role as a carer, drawing on social support for both emotional and instrumental reasons, and bereavement processes. With regard to issues of death and dying, it is suggested that participants have access to counselling facilities to help them process these experiences.

Fifthly, an increase in material resources is recommended, especially access to gloves, although implementation of these changes may be beyond the control of the organisation.

5.4. Concluding Comments

The rate of HIV/AIDS infection continues unabated and, as illustrated, the prevailing socio-economic context impacts negatively on the provision of care for PWAs. In spite of these overwhelming challenges, CHWs continue to approach their work with compassion, empathy and tolerance, and to give back the dignity that is so often lost amongst PWAs. As one carer remarked:

> "…and the patient to see (sees) that he or she is still a human being, there is someone who cares for them." LP5

Since home-based care has been posited as a way forward in treating PWAs, it is surprising that CHWs, providing the largest proportion of care in the country, are also the group that have been most neglected, underpaid and left without a voice, both by government and research academics. Why should CHWs be responsible for feeding families at their own expense, not recognised for their tireless efforts and remunerated accordingly, and not have access to medical aid, pension funds and benefits available to other government employees in the health care system? The context of care continues to impede CHWs capacity to cope effectively, in this regard government's failure to provide the necessary resources and support makes them complicit in the burnout of CHWs. What will the implications be when CHW's burn out, and are left to feel like there is no one caring for them? This will impact negatively on the on the quality of care provided to PWAs, with even more devastating consequences for general health care in the country. It is vital that carers receive care themselves, in order to continue functioning as a valuable resource in the health care system and to prevent them from feeling dehumanised.

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Appendix A

Interview Questions

DEMOGRAPHICS

Name: ______________________________

Age: ____

Marital Status: ____________

Dependents: ___________

Work Environment: _________________

Hours Worked: _____________

Monthly Income: ______________

1	Can you tell me about the type of work? ▪ Can you describe your work? ▪ What is it that you on a normal day? ▪ What are your work responsibilities/duties? ▪ How long have you been doing this work? ▪ What type of patients are you treating at the moment?
2	How do you feel about providing care to people with HIV/AIDS?
3	What aspects of the work do you enjoy? Why? ▪ What aspects of your work do you find most difficult? Why?
4	Describe a recent stressful situation with regard to one of your HIV/AIDS patients? ▪ How did you feel during this time and afterwards? ▪ What did you do during this stressful period? ▪ Is that what you would normally do? ▪ Did you talk to anyone? If not why? If Yes, Who and why that person? ▪ If you were able to talk to someone how did that help you?
5	People say this is difficult work. What helps you carry on when things feel difficult at work?
6	What happens in situations where there is nothing you can do to help the person you are caring for?

8	What is it like working with people who you know are not going to get better, how do you manage/deal with that? Can you describe a case where the patient died and what was it like for you? ▪ How did you react?
9	What do you need to help you cope better with the work you do? ▪ Do you feel you have enough emotional support?