An investigation of the coping strategies of caregivers providing home-based care for people with advanced HIV/AIDS infection.

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Abstract

The main aim of this exploratory pilot survey is firstly, to provide descriptive statistics for the Ways of Coping Questionnaire for a group of home-based caregivers within the South African HIV/AIDS home-based care context. Secondly, to examine the relationship between demographic variables (age, gender, financial status, education) and the scores on the Ways of Coping Questionnaire for the home-based caregivers. Thirdly to provide a context for the quantitative results obtained by qualitatively identifying current sources of occupational stress for the participating home-based caregivers and factors that they perceive as being able to assist them to cope better with these stressors. The questionnaire was administered to a sample of 82 caregivers from four home-based care organizations. The data was analysed using descriptive statistics to determine the coping strategies used and the reliability of the Ways of Coping Questionnaire. Results indicated that seven of the eight Ways of Coping Questionnaire subscales were not functioning reliably in this study. It was further concluded that it would not be useful to do additional comparisons of the relationship of the eight subscales with the demographic variables, as any relationships found would be weakened by the unreliability of the scales. A non-random sample of qualitative responses to two open-ended questions was analysed impressionistically. The analysis suggested that poverty, lack of medical resources, coping with helplessness and death were frequent stressors. Caregivers used their faith, support from family and colleagues as well as controlling of their emotions as ways of coping. They felt that additional training and support groups, government support, places of safety for PWAs and equipment/food would assist them to cope better with the demands of their work. It was recommended that future research adopt a more appropriate methodology given the cross-cultural and cross-linguistic difficulties evident in the study. The construction of a new coping scale suitable to the South African context is also suggested. Further research is recommended to investigate the qualitative coping experience of home-based caregivers working with HIV/AIDS, the impact of interventions to improve coping, and to explore the relationship between burnout and coping.

Declaration:

The author hereby declares that this whole thesis, unless specifically indicated to the contrary in the text, is her own original work.

Signature

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CHAPTER 1

GENERAL INTRODUCTION

1.0 Introduction

The relentless advance of the Human immunodeficiency virus (HIV) and Acquired immuno deficiency syndrome (AIDS) epidemic in South Africa places ever-increasing demands on caregivers charged with the responsibility of providing adequate care for people with HIV/AIDS. Projections of the illness indicate a prevalence of HIV in 25% of the population by 2010 (Taylor, 1998). The latest report on adult mortality rates released by the Medical Research Council of South Africa stated that they estimate "about 40% of the adult deaths aged 15-49 that occurred in 2000 were due to HIV/AIDS and that 20% of all adult deaths in that year were due to AIDS" (MRC, 2001,pp6).

In response to the increased demand for HIV/AIDS care in South Africa, a home-based system of care has been developed to provide improved quality of life to people living with HIV/AIDS (PWAs) and to reduce the stress currently placed on hospital services. Home-based caregivers provide physical, emotional and spiritual support to the individuals and their families. This has been thought to be a more cost effective and a preferable option for many of the patients (Russel & Schneider, 2000).

Caring for those with HIV/AIDS poses a multitude of challenges. The patients themselves face stigmatization, blame and misunderstanding, while the caregivers face occupational exposure risk, compounded grief due to the high level of patient mortality, and the on-going stress of dealing with the physical and emotional difficulties faced by their patients (Berkowitz & Nuttall, 1996).

Burnout describes the process of physical and psychological depletion that develops as a result of prolonged exposure to work that is demanding and stressful (Freudenberger, 1974). It has been widely reported that those in the helping profession are particularly vulnerable to burnout (Catalan, Burgess, Pergami, Hulme, Gazzard & Phillips 1996; Maslach & Jackson, 1981).

HIV/AIDS research has looked extensively at issues concerning the patient needs, while the needs of the service providers have received less of a focus (Bennett, Kelhar & Ross, 1994). Due to an on-going need to focus on AIDS prevention and patient treatment in an attempt to reduce infection rates, a focus on caregiver coping and vulnerability to burnout is not likely to receive the attention it requires. Caregiver coping has therefore been identified by the researcher as a new field of interest, requiring exploration within the field of HIV/AIDS research in the South African context.

1.1 Background to the study

Caregiver turnover and burnout pose a huge problem to the South African health care system, a system that is already struggling to cope with the current AIDS crisis. These caregivers are vulnerable to burnout, given the nature and social context of their work. Despite this, many of the caregivers manage to cope with the work they do and it is of interest to understand and describe how they cope and what facilitates such coping.

1.2 Rationale for the study

Given the importance of the work provided by home-based caregivers for those who are HIV positive or who have AIDS in the South African context, and the difficulties many are experiencing coping with this work, what influences or enables such coping is of interest. Understanding how caregivers do cope in the face of vulnerability to burnout can inform interventions aimed at improving other home-based caregivers' abilities to cope with similar work-related stresses, as well as inform others regarding coping in the helping profession in general.

Studies show that there are certain coping variables i.e. Escape-Avoidance, Positive Reappraisal and Social Support from Family, that are significant predictors of burnout, as well as other variables that are effective moderators that can assist individuals in dealing with burnout (Florence, 1998).

During preliminary meetings with the organisations participating in this study, it was evident that they had begun to identify the provision of care and support for their carers as a critical challenge. The Caring Network specifically, wanted to obtain feedback from the present study, to motivate for the funding of this aspect of their organisations' needs. The results could also be of benefit for other organisations to learn from the experiences of colleagues who are coping with similar challenges and could lead the way for further studies in this field.

1.3 Significance of the research

The present study is exploratory in nature. It is the first of its kind focusing specifically on caregiver coping within South African HIV/AIDS home-based care context. Home-based care organisations in South Africa are acknowledging the importance of focusing on care for the carers and many are currently in the process of establishing programmes to assist their caregivers. This study could be used as a pilot for further evaluative research in this area. It provides a description of the coping strategies used by caregivers for PWAs which could be used to inform intervention strategies, support and training for caregivers and to increase their effectiveness and ability to cope with the demands of their work.

1.4 Overview of chapters

The remainder of this thesis is detailed in four chapters. Chapter 2 presents a theoretical framework and understanding of the concepts of stress, coping and burnout. An overview of existing literature, as well as the inter-relationship of these three concepts is also provided. The review also focuses specifically on the application of these concepts to an understanding of the work done by caregivers of PWAs. It reviews HIV/AIDS research in South Africa with specific reference to caregiver research. Chapter 3 provides an overview of the methodology employed to collect and analyse the data presented. It notes the aims and objectives of the study. It identifies the participants who partook in the study, describes the overall research design used, as well as presenting the research tool - the Ways of Coping Questionnaire (WCQ). The chapter outlines the eight sub-scales of the questionnaire, its psychometric properties and motivates for its use in this study. The chapter also details the procedures followed to enable the completion of the study, describes the methods used to analyse the data as well as the ethical considerations that were taken into account during the study. Chapter 4 provides quantitative and qualitative results emerging from analysis of data collected. In conclusion, Chapter 5 discusses and explains the results, the practical implications of the results, the limitations of the study as well as recommendations for future research.

1.5 Chapter Summary

The aim of this chapter was to give an overview of the HIV/AIDS epidemic in South Africa, highlighting the paucity of research focusing on the difficulties experienced by caregivers in the current context. The chapter states the significance of the study as well as a background and rationale for the research presented. Finally, it concludes with a concise layout of the content of the remaining chapters.

CHAPTER 2

LITERATURE REVIEW

2.0 Introduction

This chapter aims to review and discuss, both theoretically and practically, the concepts of stress, coping and burnout and how an understanding of their relationship to each other is relevant when looking at the work of caregivers of PWAs. It highlights factors that impact upon a person's ability to cope with stressful encounters. It then reviews caregiver research conducted in South Africa to date. Finally, it investigates home-based care work currently being done in South Africa for PWAs.

2.1 Conceptualising stress

Interest into understanding the concept of stress has captured both scientific and popular attention due to its existence in many aspects of our current daily living. Lazarus and Folkman (1984) assert that stress, coping and adaptation pose both an individual psychological and physiological human problem as well as a societal problem.

Definitions of stress have raised much debate and discussion, and clarification of the term is important as it impacts upon how it is researched and how results are then explained. The term “stress” was technically used in 1936 by Hans Seyle in reference to the body’s defence against any noxious stimulus (Lazarus & Folkman, 1984). Lazarus and Folkman (1984, pp19) define stress as “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his/her resources and endangering his/her well-being”. This definition takes into account the characteristics of the person and the nature of the environmental event and parallels modern conceptions of illness being the result of external organisms. Stress in the work environment involves an interaction between the individual and the environment, and is a result of the interaction between environmental demands and insufficient environmental supplies (Hilburg, Nathan & Thoreson, 1986).

Definitions of stress fall predominantly into three approaches: stress as a stimulus, stress as a response and stress as an interaction between the environment and the person (Bailey & Clarke, 1989).

2.1.1 Models of Stress

A stimulus-based model of stress conceptualizes stress as an external stimulus to which an individual responds (Bailey & Clarke, 1989). Stress would be seen as an independent variable in a study and it would be required that stimuli that are considered as stressful be defined. Stress would thus be an external force that impacts upon a caregiver. Criticisms of this model are that stress cannot simply be seen in terms of cause and effect, and that it does not take into account the coping abilities of individuals (Bailey & Clarke, 1989).

A response model of stress seeks to define stress as a non-specific stereotyped response of the body. This General Adaptation Syndrome (GAS), coined by Seyle, comprises three stages, namely; alarm reaction, resistance and exhaustion (Bailey & Clarke, 1989). Seyle (cited in Bailey & Clarke, 1989) commented that whatever changes we are presented with, ultimately we are presented with the same dilemma, that is adaptation in the interest of continued wellbeing. This model suggests that many causes of stress can produce the same physiological effect. Seyle implicated psychological factors in the cause and progress of disease as well as the role of the adrenal cortex in stress (Bailey & Clarke, 1989). Criticism of this model relates to its conception of people being passive, and merely reacting to a hostile environment (Bailey & Clarke, 1989).

A cognitive-phenomenological-transaction model of stress attempts to address the shortcomings of the previous two models (Lazarus & Folkman, 1984). The model is cognitive in that it takes into account thinking, memory and meaning as mediators in the determination of stress and coping. It is phenomenological, as an individual's appraisal of an event influences their response to it and it is transactional in that it highlights the interaction between appraisals made and the environment in which they occur (Bailey & Clarke, 1989).

Lazarus (cited in Carver, Weitraub & Scheier,1989) notes that stress comprises of three processes. Primary appraisal, perceiving a threat to oneself; secondary appraisal, is the process of bringing to mind a potential response; and coping the execution of the response. The process is not linear and may cycle repeatedly in a stressful situation. Lazarus and Folkman (1984) note that situational factors (i.e. novelty, ambiguity, timing, commitments and beliefs) are important determinants of appraisal of a stressful event.

Bailey and Clarke (1989) assert that this model of stress seems to be the most applicable and useful as a framework for studying nursing practice and for this reason it was selected as the most appropriate model for this study. They also state that it is easily applicable to real life, it sees the individual within his/her context, and it provides a framework for individuals to cope or improve coping abilities in the face of stress (Bailey & Clarke, 1989).

2.2 Defining Coping

The literature defines coping in a variety of ways. According to Sarifin (1994), coping is a cognitive and behavioural response used to deal with a stressful situation. Stress involves a perceived discrepancy between the demands of a situation and the resources that a person has to deal with. Coping thus involves attempts to manage this perceived discrepancy between situational demands and the resources available (Sarifin, 1994).

Lazarus and Folkman (1984) classify coping responses as problem-focused and emotion-focused. Problem-focused coping involves reducing the demands of a stressful situation or increasing the resources required to cope with the stress. Problem-focused coping is generally used when individuals believe their resources or the demands of the stressful situation are changeable. Examples of problem-focused coping include bargaining, focus on the positive, social support and concentration of efforts (Sarifin, 1994).

Emotion-focused coping is used to control the emotional response that one has to a stressful situation. Emotional responses can be altered using behavioural or cognitive methods. Emotion–focused coping is generally used when individuals believe they are unable to change a stressful situation. Examples of emotion-focused coping include wishful thinking, detachment, and acceptance (Sarifin, 1994). Both methods of coping are used to differing degrees to cope with stressful situations and change according to situational demands.

Lazarus and Folkman (1989) note that an individual's interaction with the environment generates emotions that in turn produce bodily responses. Individuals constantly appraise events and generate behavioural strategies to deal with their appraisals. This primary appraisal of events allows the individual an opportunity to plan a response and avoid blindly encountering danger (Lovallo, 1997). A secondary level of appraisal is then used to evaluate the coping options considered, which in turn determines one's cognitive and behavioural response as well as one's emotional, neurophysiological, autonomic and endocrine response to external events. Lazarus and Folkman (1984) note that our beliefs about how the world should work and our commitment to a course of action determine our primary appraisal of events. The interventions used at a secondary level of appraisal are what we understand as coping strategies or coping behaviour. They include covert and overt activities (Lovallo, 1997).

Lazarus and Folkman (cited in Wineman, Durand & McCulloch, 1994) define coping as follows; "the constantly changing cognitive and behavioural efforts used to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (pp.141). Coping is thus conceptualized as a dynamic process that is dependent on the person - environment transaction.

Coping can occur at different levels: (a) by individual caregivers, (b) at a group level to assist others (social support) and (c) at an organisational level (Shinn et al. ,1984).

Lazarus and Folkman (1984) note that their definition of coping and the instrument developed to assess coping, The Ways of Coping Questionnaire, has four key features: 1) it is a process oriented approach; 2) it addresses management rather than mastery; 3) it makes no a priori judgement about the quality of the coping process; and 4) it implies a stress-based distinction between coping and automatic adaptive behaviour.

Coping thus involves the thoughts and actions of an individual as well as how these thoughts and actions unfold as a dynamic process. Lazarus and Folkman (1984) do not see coping hierarchically as a mature ego defence, rather it must be viewed relative to adaptational outcomes in specific contexts. Certain behaviour can thus be adaptive in one context and maladaptive in another. Coping is conceptualized not as an automatic response, but it is an adaptational response that requires effort and does not refer to all things we do in relation to the environment (Lazarus & Folkman 1984).

2.2.1 Factors that influence coping

In studies using the Ways of Coping Questionnaire the choice of coping strategies used appeared to be influenced by factors such as self-esteem, whether stress experienced involved family members, and the degree of control an individual felt they had over the stressful situation (Lazarus & Folkman, 1989).

A greater use of Self-Control, Confrontive Coping, Accepting Responsibility, Escape-Avoidance and a reduction in Seeking Social Support is used when a person feels that their self-esteem is threatened (Lazarus & Folkman, 1989).

A greater use of Confrontive Coping, Escape-Avoidance and a reduction in the use of Planful-Problem Solving and Distancing are used when a loved one's wellbeing is threatened (Lazarus & Folkman, 1989).

A greater use of Confrontive Coping, Accepting Responsibility, Planful-Problem Solving and Positive Reappraisal indicates that encounters appraised are viewed as changeable (Lazarus & Folkman, 1989).

A greater use of Distancing and Escape-Avoidance indicates that encounters appraised are viewed as unchangeable (Lazarus & Folkman, 1989).

Florence (1998) highlighted the fact that the context in which a stressful event occurs as well as demographic variables of age and gender influence the coping strategies used by individuals to cope with stress. According to Florence (1998), the literature suggests that problem-focused coping is more effective than emotion-focused coping.

Women are seen as being more inclined to use emotion-focused coping. It was also found that coping, social support and hardiness as the three most important moderators of burnout (Florence, 1998). McColl and Skinner (cited in Florence, 1998) confirm that coping and social support can be predictors of stress outcomes, further suggesting that the two are modifiers that are most likely to be amenable to therapeutic manipulation.

2.3 Burnout

Munnik (2000) notes that chronic stress in the absence of adequate coping strategies plays a pivotal role in the development of burnout. The distinction is made between stress and burnout, with burnout being conceptualized as a response to the chronic stress involved in dealing with people, in particular people in distress (Munnik, 2000).

Burnout is commonly defined in existing literature as the report of emotional exhaustion, and the inability to give emotional support to others (Bennett et al., 1994). The term burnout was introduced by Freudenberger in the seventies, with many subsequent definitions being offered (Shirom, 1989).

Maslach and Jackson (1981) have put forward one of the most widely used definitions of burnout. This definition has formed the basis for the development of the Maslach Burnout Inventory (MBI) which is a commonly accepted valid instrument in caregiver burnout studies.

Burnout is defined as a combination of three components:

1. Emotional exhaustion: Individuals feel exhausted and emotionally over-extended by their work (Bennett et al., 1994).

2. Depersonalization: Individuals feel emotionally detached and adopt an impersonal response to patient/clients (Bennett et al., 1994).

3. Lack of Personal Accomplishment: Individuals tend to evaluate themselves negatively, in relation to work and are dissatisfied with their accomplishment at work (Bennett et al., 1994).

Maslach (1982) proposes that burnout is a result of an interaction between the individual and their environment. To understand burnout more comprehensively, one has to look at the context in which it occurs.
Factors such as a perceived lack of control, as well as relations with superiors, contribute to high levels of burnout of staff (Maslach, 1982).

2.4 The relationship between stress, burnout and coping and its relevance for caregivers

When trying to understand how individuals cope with stress, it is important to understand the relationship between stress, coping and burnout. Coping is the mechanism whereby individuals attempt to deal with stress or moderate the effects of stress in order to prevent burnout, and thus these concepts are inextricably linked.

It is widely acknowledged that nurses, and caregivers in general, work in environments that contain many and varied stressors and are therefore susceptible to burnout (Nixon, 1995). A consequence of caregivers having to cope with excessive demands is that they often experience debilitating exhaustion. Burnout interferes with and disrupts the relationship between the caregiver and the patient.

Ogus (1992) conducted a study to look at burnout and coping strategies in surgical ward nurses and medical ward nurses. She found that nurses using high levels of maladaptive palliative coping (this involves regulating emotions without solving the problem) experienced greater burnout, and nurses using high levels of preventative and/or existential coping reported lower burnout. She also noted that medical ward nurses experienced greater burnout and used significantly more maladaptive coping strategies (e.g. crying, sleeping less, eating more) than their surgical counterparts (Ogus, 1992).

Dewe (1989) investigated the relationship between stressor frequency, tension, tiredness and coping across different nursing groups. He reported that one must be cautious of an oversimplification of one's approach to stress measurement.

When viewing coping, it is important to distinguish individual resources from organisational resources. Staff shortages, dealing with too many patients, shiftwork and a perceived lack of support from the organisation impact on experiences of stress and coping. Similarly, support systems, clear instructions, clearly defined work routines and training can assist nurses to deal with stress (Dewe, 1989). The researcher also stressed the importance of recognising the transactional nature of stress, and that merely changing stressful aspects of the job does not necessarily provide supportive and positive structures for nurses to grow and develop.

Dewe (1993) investigated the effect of coping on stressors. He looked at nurses and the association between the frequency of nurses' coping and the intensity of their work stressors. Results indicated that the greater use of coping strategies was associated with more stressors, tension and fatigue. A greater reliance on emotion-focused coping could reflect the lack of resources and control available to nurses, who may feel that they only have control over their emotions (Dewe, 1993).

2.5 HIV/AIDS care and its impact on caregivers

With the increase in the number of HIV/AIDS cases and the subsequent increase in people requiring care, health care workers face the resulting responsibility of providing the prolonged and intensive care required by PWAs.

Barbour (1995) notes that because the demands placed on AIDS caregivers have been so immediate, the provision of appropriate care has been of prime importance. This has meant that there has not been much of a focus on what caregivers find the most challenging about their work with PWAs, how they are coping with these challenges and how these experiences of changing work demands have affected them.

Researchers note high caregiver turnover rates and reports of burnout in organisations providing care for HIV/AIDS (Bennett, Michie & Kippax, 1991; Bennett, Kelhar & Ross, 1994; Sherman, 1996).

Driedger and Cox (1991) investigated the relationship between burnout and social support, and the difference in the coping styles of nurses that cared for PWAs versus those that don't. They found that social support was not significantly predictive of burnout and inexperience was significantly related to the level of emotional exhaustion reported by nurses. Coping styles, as measured by the WCQ, did not vary significantly between the two groups, but nurses caring for PWAs expended 21% of their total coping effort on Seeking Social Support and 20% on Planful Problem Solving. On the other hand, nurses not caring for PWAs used 23% of total coping effort on Planful Problem Solving and 18% on Seeking Social Support.

Sherman (1996) found that a willingness to care for AIDS patients was positively correlated with spirituality and perceived social support, and negatively correlated with death anxiety. She also noted that group culture or professional identity could possibly mediate nurses' willingness to care for AIDS patients.

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Barbour (1994) reviewed studies that looked at the impact of caring for PWAs. She found that determinants of burnout in caregivers were related to the young age of the patients that were dying, neurological conditions presenting as a result of HIV/AIDS related illnesses and the issue of bereavement overload. She also found that because of the slow course of the disease, many caregivers have more intimate contact with patients and that this can present further difficulties for caregivers. Stresses involved in AIDS work specifically are also seen as a consequence of the diversity of the client population. They include difficulty in dealing with neurophysiological aspects of the illness, particularly in view of many caregivers having limited previous experience of psychiatric care. Barbour (1994) also raises a discussion about the impact of caregiver characteristics influencing their vulnerability to psychological distress. Specifically training, previous experience, age, personality and sexual identity are noted as influencing the caregivers' adaptation to the demands of HIV/AIDS-related work.

Bennett et al.(1991) examined burnout and its associated factors in nursing care of AIDS patients. They noted that when compared to burnout in oncology nurses, AIDS nurses showed a greater intensity of burnout. Length of time working with AIDS patients was identified as increasing the likelihood of burnout, while age was inversely related to burnout. Bennett et al., (1991) also notes higher levels of patient dependency with AIDS patients, as the patients require greater amounts of care. This then is suggested as influencing the intensity of emotional exhaustion measured in the caregivers. They also note that the stigma associated with AIDS care and the age of the patients may be further contributing factors to the intensity of emotional exhaustion.

Catalan et al., (1996) looked at the psychological impact and levels of occupational burnout experienced by staff involved in AIDS care and oncology using the MBI. Reports of significant measures of work-related burnout were found in a fifth of the sample. AIDS workers reported significantly lower levels of personal accomplishment, both in terms of frequency and intensity. The researchers found that staff used informal support groups to cope with difficulties experienced and would be likely to respond to interventions aimed at improving their ability to cope with their work-related stresses.

Klonoff and Ewers (1990) investigated the sources of stress associated with care of AIDS patients. They note that nurses identified three sources of stress associated with AIDS care. Firstly, nurses were concerned about the transmission of the virus and because of this they needed thorough training regarding specific methods of care. Secondly, they experienced anxiety concerning the use of invasive interventions and thirdly, they felt stress related to family and friends' attitudes and concerns about their work.

Horsman and Sheeran (1995) reported that HIV/AIDS care raises issues of fear of infection, attitudes towards sexuality, fear of social stigmatisation and concerns about caregivers having a right to refuse care for PWAs. Particularly within the hospital environment, economic pressures and employment difficulties can mean that healthcare workers feel obliged to provide such care. In addition to this, health care workers face the high levels of patient mortality and increased work demands, as the care requirements of PWAs is estimated at being 40% greater than those patients who are terminally ill with cancer (Horsman & Sheeran, 1995).

Berkowitz and Nuttall (1996) looked at the attitudes of pediatric nurses facing HIV risk. They found that greater occupational experience of caring for PWAs resulted in more positive attitudes towards care. While a majority of the nurses expressed a willingness and responsibility towards such care, they noted that their families and friends were concerned about their occupational risk (Berkowitz & Nuttall, 1996).

Bennett and Kelhar (1993) used the WCQ, Maslach Burnout Inventory (MBI) and Social Support Evaluation List (including a measure of relationship stability) to measure the different strategies used by staff to cope with losses associated with AIDS care. The WCQ was used to understand which variables contribute to experiences of grief by healthcare professionals. They found that the most effective coping strategies used involved the use of internal resources rather than relying on external agencies to change the situation. Internal coping strategies included positive, self-expressive, active, vigilant and time-out coping strategies. It is asserted that higher levels of burnout are associated with external coping strategies. They suggested that one's coping style might be an important moderator of the effects of grief. The results also highlighted the importance of support for staff working in the area of HIV/AIDS, as increased support is more likely to reduce strong feelings of grief (Bennett & Kelhar, 1993).

Bennett, Kelhar and Ross, (1994) examined why burnout occurs and how it can be prevented in the care of patients with HIV/AIDS. They noted that higher burnout scores were linked to the use of mental and behavioural disengagement as a primary coping strategy. They proposed that coping styles influence the levels of experienced burnout. It is further suggested that education about coping may assist caregivers to deal with the difficulties related to HIV/AIDS care. These researchers found that the social context was an important determinant of burnout and that high burnout was associated with higher levels of external coping. They suggest that instruction regarding internal coping skills is one of the ways to reduce burnout.

Sikkeman and Kalichman (1995) describe the use of a cognitive-behavioural coping model for improving one's ability to cope with AIDS related bereavement. They ran support groups based on a model comprising six components: social support and group cohesion; identification and expression of emotion; identification of specific coping challenges of AIDS loss; recognition of current coping using the WCQ; goal setting and implementing adaptive coping. They found that their intervention appeared to facilitate adjustment of bereaved individuals and recommended further studies in the field (Sikkeman & Kalichman 1995).

Catalan et al. (1996) identified coping strategies used by staff to cope with the psychological stress experienced in their work with AIDS patients. They noted the use of informal methods of support, such as speaking to colleagues, as a useful way to cope with the demands of their work.

2.6 HIV/AIDS within the South African context

According to current UNAIDS statistics for South Africa, there are a total of 4.2 million infected people, the largest number of people living with HIV/AIDS in the world, as well as one of the world's fastest-growing epidemics (UNAIDS, 2001). Projections indicate that without adequate treatment to prevent AIDS, the number of deaths can be expected to more than double in the next decade, resulting in 5 to 7 million cumulative deaths in South Africa by 2010 (MRC, 2001). Data reveals that mortality rates of women age 25-29 in 1999/2000 are 3.5 times higher than in 1985 (MRC, 2001). These statistics alert one to the demands that are then placed on caregivers of PWAs. To comprehensively understand the AIDS epidemic in South Africa, it must be located within a context of a social legacy of segregation, poverty and a lack of access to basic services by the vast majority of the population (Taylor, 1998). One cannot merely view the spread of this virus from a medical perspective, as access to the socio-economic circumstances required for adequate health, are not available to the majority of the population of South Africa. This in turn affects the access that the majority of PWAs have to health services and appropriate care.

The public health sector faces increases in new cases of tuberculosis as a result of HIV/AIDS, rapidly rising hospital admissions and severe budgetary constraints (Taylor, 1998). Due to the rapid growth of the number of PWAs, there has been a demand for alternatives to hospital treatment. In an attempt to deal with such demands, common practice permits health care facilities to ration services to people with HIV, leaving the burden to fall onto households and communities (Russel and Schneider, 2000).

2.7 Community-based care

Home-based care was initiated as an alternative to hospital care to cater specifically to the needs of PWAs. Home-based care is explained by Sims (1992) cited in Roos(1997) as “caring for the patient and those important to him/her as a unit. When successful, care provided in the familiar surroundings of the home, with the multi-professional input from statutory and voluntary services, can produce the very best of terminal care” (pp26.)

The predominant literature on community-based care and support has emerged from Botswana, Zimbabwe, Zambia, Tanzania, Malawi and Uganda since the late

1980's and includes some of the following models: The AIDS Support Organisation (TASO) in Uganda; Family AIDS Caring Trust (FACT) in Zimbabwe; Catholic Diocese in Ndola in Zambia's Copperbelt (Russel and Schneider, 2000).

Russel and Schneider (2000) note that the benefits of community-based care include:

- Reduced incidence of hospitalisation and shorter stays
- Reduced costs to the family
- Decreased isolation of PWAs
- Increased support for family members
- Increased possibility of drug compliance by giving education and support to PWAs and their families
- Reduced burden on primary care system due to better education in nutrition and general wellness

Given the reality that most HIV/AIDS patients spend the majority of their illness at home, having home-based care services makes it easier for hospitals to discharge seriously ill patients as they know support is available (Russel and Schneider, 2000). The South African health service has instituted a system of home-based care to address the current demands. This service is more cost-effective, and it allows the patients to be cared for in the privacy of their own homes. Hospital care is primarily curative, and this is seen as inappropriate to people living with a terminal illness. Home-based care has been judged more appropriate for AIDS-related illnesses, which do not need intense medical intervention, but rather require long-term nursing care (Soal, 1997).

Russel and Schneider (2000) critically note that while there have been efforts to develop alternative community-based care structures, decades of experience in implementing primary health care have shown that community involvement in health services is difficult to sustain and hard to institutionalise. They also add that evaluations in other southern African countries have challenged the idea that home-based care is in fact a quick-fix and cost effective alternative to hospital-based care (Russel and Schneider, 2000).

Roos (1997) argues that home care is also extremely important as a preventative intervention, as this form of care involves the family and the community. Carers are able to promote knowledge about AIDS and how to avoid it.

Soal (1997) notes that home-based care was identified by the National Aids Convention of South Africa (NACOSA) as a vital aspect of a national AIDS strategy to address the social and personal impact of HIV. It has been found that AIDS patients and their families prefer home care when given the choice, but studies done in KwaZulu/Natal showed that only a small portion of the people in need of home care services were reached (Soal, 1997).

Current models of community–based care and support in South Africa include 5 common program types, with the fourth and fifth models being the focus of this study:

1. Funding, technical assistance and support programs
2. Advocacy and community mobilization

3. Drop-in centres/support programs giving counseling and running support groups
4. Community-based care programs providing the above and home visits
5. Comprehensive home-based care programs providing the above plus varying levels of nursing care (Russel and Schneider, 2000).

The minimum care package provide by home based–care organisations includes: education to family members and PWAs; supportive visiting of PWAs; accompanying PWAs to clinics; food provision where possible; basic bandaging; cleaning and bathing; running minor errands, and referral to other support services where required (Russel and Schneider, 2000).

Russel and Schneider (2000) note that community-based care, if integrated with prevention strategies, can have a positive impact on decreasing the spread of HIV/AIDS. They also state that such care results in greater community acceptance and a normalisation of the disease, creating greater openness for PWAs to disclose their status.

2.8 Caregiver research in South Africa

Current South African studies of health care workers have focused more on the existence of burnout and have not looked at coping strategies used by these health care workers. There are numerous studies focusing on stress and burnout amongst nurses in South Africa (Cube, 1998; Ferrett, 1999; Govender, 1995; Munnik, 2000; Ngobo, 1997; Nixon, 1995; Van der Merwe, 1982; Van der Merwe, 1993; Venter, 1993). Cube (1998) investigated a sample of 46 health care workers consisting mostly of professional nurses and determined the existence of moderate levels of burnout.

Munnik (2000) looked at burnout amongst community mental health nurses in the Metropolitan Region of the Western Cape. She found a moderate degree of burnout, with high levels of emotional exhaustion. She attributed possible personal and organisational variables as possible contributors to these findings (Munnik, 2000). These studies do not address specifically the care of people with HIV/AIDS, and they focus specifically on care within the hospital environment.

2.9 AIDS Care research in South Africa:

There has been limited South African research that focuses specifically on care of people with HIV/AIDS (Raphela, 1997; Soal, 1997). Soal (1997) evaluated a community health pilot project initiated to care for PWAs and highlighted issues involved in caring for PWAs, such as the need for training and counseling skills and the difficulties related to multiple losses.

Russel and Schneider (2000) held focused discussions with 21 PWAs and care providers from an urban township near Pretoria. They asked those interviewed to comment on the needs of those infected and identified the following themes emerging from the interviews: poverty and isolation; hunger; fear for their children; difficulty accessing welfare grants; fear and acceptance; and the lack of male participation in HIV/AIDS services.

Further interviews with home-based care organisations revealed that a willingness to volunteer varied from community to community and seemed to be influenced by a sense of belonging to the community. It was found that in the Western Cape and KwaZulu-Natal programs were more successful. Care organisations also noted that confidentiality often made them invisible, as they could not admit to providing AIDS services and this lead to low caseloads (Russel and Schneider, 2000).

The literature reviewed on stress, levels of burnout found in AIDS care and a knowledge of the increasing demands being placed on home-based caregivers within the South African context highlights the need for investigations in this regard. Understanding how caregivers are able to cope is thus a critical component of ensuring that caregivers are able to provide the high quality care required by PWAs.

A study of coping will thus enable a more comprehensive understanding of how individuals manage to provide such a service in the face of adversity. Investigating AIDS care within a community-based care context in South Africa allows the changes in service provision and the impact this has had on caregivers to also be taken into account.

An investigation into coping strategies of HIV/AIDS caregivers is therefore undertaken to begin to address the paucity of information in this area. This primarily descriptive study represents a contribution towards addressing this situation, the rationale being that findings can eventually be assimilated into training and support programmes, and ultimately the adequate treatment of PWA's can be improved and maintained.

2.10 Chapter summary

This chapter detailed an overview of the concepts of stress, coping and burnout in the literature. It described the relationship between stress, burnout and coping. It focused on the factors that impact on a person's ability to cope with stress. It contextualized HIV/AIDS within the South African health care system, as well as discussing the current literature on community-based care for PWAs, caregiver research in South Africa, and current models for care for PWAs in South Africa.

CHAPTER 3

METHODOLOGY

3.0 Introduction

This chapter details the methodology employed in the present study. It commences with the aims of the study, and the research questions that are addressed. This is followed by an explanation of the research design and a layout of the demographic variables of the study's participants. It then provides a description of the research tool, The Ways of Coping Questionnaire (WCQ), its eight sub-scales and their psychometric properties. The data collection and analysis procedures used are then outlined. Finally, ethical considerations are discussed.

3.1 Aims of the study

The central aims of the present pilot study are firstly, to provide descriptive statistics for the Ways of Coping Questionnaire for a group of home-based caregivers within the South African HIV/AIDS home-based care context. Secondly, to examine the relationship between demographic variables (age, gender, financial status, education) and the scores on the Ways of Coping Questionnaire for the home-based caregivers.

A secondary aim given that this is a pilot study, is to qualitatively identify current sources of occupational stress for the participating home-based caregivers and factors that they perceive as being able to assist them to cope better with these stressors.

3.2 Statement of the research problem

On the basis of the aims stated above, the following quantitative research questions will be explored:

- Does the Ways of Coping Questionnaire provide sufficiently reliable scores in a study of a South African group of home-based caregivers of people living with advanced HIV/AIDS infection?
- Is there a significant relationship between certain demographic variables (age, gender, financial status, education) and the coping strategies used by home-based caregivers of people living with advanced HIV/AIDS infection?

To provide a context for the understanding of the quantitative questions investigated, the following qualitative questions will be explored:

- What are the most stressful aspects of providing home-based care to people living with advanced HIV/AIDS infection and how do caregivers cope with these difficulties?
- What strategies are perceived by caregivers as being able to assist them to cope better with the demands of their work?

3.3 Research Design:

This pilot study took the form of a descriptive, exploratory, correlational field survey using non-probability sampling procedures (Kerlinger, 1986). Data was collected retrospectively by means of a self-report questionnaire. The first part of the study, aimed to describe the coping strategies used by caregivers in terms of the WCQ and the reliability of the research instrument within this context. This was done using descriptive statistics such as means and standard deviations. Based on the findings of the first part of the study, the second part of the study aimed to determine the effects of various demographic variables on the type of coping strategies employed by caregivers. This design was considered appropriate for examining the associations between coping strategies and demographic variables, given that this is a relatively new area of research within the South African context. It also has the ability to provide the basis for a preliminary, exploratory examination of coping in this context the relationship between coping strategies and demographic variables. Qualitative data comprised of a commentary of the researchers impressions from observational data obtained from contact with caregivers on home visits to PWA's and via the review of a non-random selection participants responses to two open-ended questions posed in the questionnaire and was used to provide a context for the interpretation of the quantitative results.

3.4 Participant selection and procedure:

The participants consisted of a non-probability convenience sample of 82 home-based caregivers from four selected organisations (The Red Cross Society, The Caring Network, The Namaqualand Aids Project (NAP), and Koinonia) currently involved in the provision of care for people living with HIV/AIDS in the Western and Northern Cape.

The following 5 organisation were approached, and 1 - 4 elected to participate. The reasons for the fifth organisation deciding not to participate are discussed in a later chapter.

1. The Caring Network – A Catholic based community outreach programme servicing Crossroads/Nyanga, Gugulethu, Wallacdene, Driftsands, Phillipi, Site B, Mfuleni, Mbekweni and Bishop Lavis.
2. Koinonia – A non-governmental organisation based in Kuilsriver servicing the surrounding community.
3. The Red Cross Society – A non-governmental organisation based in Wynberg, providing home-based care in the Western Cape.
4. The Namaqualand AIDS Project – A community organisation based in Calvinia, providing home-based care to the Karoo/Northern Cape Region.

5. Joy for Life – A non-governmental organisation based in Cape Town providing care, training and support to PWAs and their families.

Co-ordinators from the organisations were contacted personally by the researcher and permission was requested to conduct the study. Once permission was granted, the researcher explained to the co-ordinators how the questionnaires needed to be completed and they agreed to distribute and assist caregivers with the completion of the questionnaires if needed. The co-ordinators supplied all home-based caregivers working for these organisations with a written explanation of the purpose of the study and a request for their voluntary participation.

From feedback following the completion of the questionnaire, it was evident that there had not been consistency of administration of the questionnaire. Co-ordinators from the Caring Network had met with the caregivers and had got them to complete the questionnaires in their presence, while the other organisations had given the questionnaires to the caregivers and collected them on completion. The Caring Network wanted to use the results from the study to motivate for the funding of support for their caregivers, and was willing to ensure that information was obtained for this purpose.

The Caring Network noted that their caregivers had particular difficulties with regard to language constraints as many of the caregivers were Xhosa speaking and required additional assistance with the Xhosa scale employed. They noted that many of the caregivers had never filled in a questionnaire before and that they had difficulties with the level of Xhosa translation of the scale.

An example of the abovementioned request and questionnaire is furnished in Appendix A.

3.5 Demographic details:

Participants were requested to provide the following demographic details: age, gender, home language, marital/cohabitation status, details of their children, religion, religiosity, education, the area where they live, financial circumstances (number of people in the home, number of rooms in the home, monthly income and total financial contribution of the household), work experience in home-based care, previous work experience and the number of patients currently in their care.

With regards to the coding of the demographic data obtained from participants, the data was categorized and assigned nominal numerical values. A demographic codebook is presented in Appendix B.

3.6 Description of participants:

The questionnaire was given to 124 caregivers from four organisations The total return of the questionnaire was 66% (n=82) of the total population (see Table 1).

(n=24) had Matric and 13% (n=11) had primary school qualifications. One participant had a Nursing Diploma.

All of the participants (100%) were members of the Christian faith, with variations in their commitment to practicing their faith. 56% (n=46) reported attending church weekly. Missing data was minimal for most of the demographic details requested by the caregivers, it is proposed that the missing data may be due to a lack of understanding of the question posed or that certain questions may have not been applicable.

Table 2 : Participant Demographics: Descriptive Statistics

VARIABLE	n	%
TOTAL N=	82	100%
AGE: < 20	1	1 %
20-29	21	26%
30-39	29	35%
40 – 49	16	20%
> 49	14	17%
Missing data:	1	1%
MARITAL STATUS:		
DIVORCED	10	12%
MARRIED	33	40%
SEPARATED	8	10%
COHABITING	20	24%
LIVING ALONE	5	6%
WIDOWED	4	5%
Missing data:	2	3%
LANGUAGE:		
XHOSA	52	63%
AFRIKAANS	21	27%
ENGLISH	1	1%
ENG AND AFR	6	7%
OTHER	2	2 %
How religious they regard themselves. LIKERT SCALE 1(very religious) to 7 (not at all religious)		
1	34	41%
2	21	26%
3	17	21%
4	6	7%
5	3	4%
Missing data:	1	1%
RELIGIOUS ATTENDANCE:		
WEEKLY	46	56%
MONTHLY	22	27%
LESS THAN MONTHLY	8	10%
NOT AT ALL	6	7%
NO. OF PATIENTS IN CARE :		
0-1 person	33	40%
2 people	4	5%
3-6 people	16	20%
7-10 people	6	7%
> 10 people	16	20%
Missing data:	7	8%

Table 3 details information regarding the participants current living circumstances, work experience and patient load in order to better understand the stressors faced by home-based caregivers. Again missing data was minimal for most of the demographic details requested by the caregivers, the missing data may also be due to a lack of understanding of the question posed or that certain questions may have not been applicable. The majority of participants (66%; n=54) lived in an area classified [1]by the researcher as an African township, while 32% (n=26) lived in an area classified by the researcher as a “Coloured” township. Most of the sample 71% (n= 58) currently live in houses with 3 – 4 total inhabitants, whilst 21% (n=17), live in houses with 2 rooms 68% (n=56). The majority of the sample earn a monthly income of R500 or less per month and the recorded total monthly contribution to households fell predominantly below R500, 56% (n=46).

34% (n=28) had been working in the field of home-based care for between 2-3 years, with 12% (n=10) of the participants having more than 6 years experience providing home-based care. With regards to previous work experience, 7% (n= 6) had previously worked as nurses, while 34% (n=28) had been employed as domestic/blue collar workers. Currently, 40% (n=33) caregivers, were looking after 1 patient, while 38 % (2 X n=16) were caring for between 3-6 patients and more than 10 patients respectively.

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[1] The classification of area has been done in terms of racial classification terms used by the previous Apartheid government. This is a controversial classification system but it has been used for descriptive purposes in this study as it impacts today on the geographical location of many of the population still.

Table 3: Participant Demographics: Socio-economic variables

VARIABLE	N = 82	100 %
EDUCATION LEVEL :		
PRIMARY	11	13%
SECONDARY SCHOOL	43	52%
MATRIC	24	29%
NURSING DIPLOMA	1	1%
OTHER	1	1%
Missing data:	2	4%
AREA :		
AFRICAN TOWNSHIP	54	66%
COLOURED TOWNSHIP	26	32%
INFORMAL SETTLEMENT	2	2%
NO. OF ROOMS IN HOUSE:		
1 ROOM/SHACK	11	13%
2 ROOMS	17	21%
3 ROOMS	17	21%
4 ROOMS	20	24%
> 4 ROOMS	16	19%
Missing data:	1	2%
MONTHLY INCOME:		
R500 or less	56	68%
>R500 –R1500	17	21%
>R1500 – R2500	3	4%
>R2500 – R3500	2	2%
>R3500	3	4%
Missing data:	1	1%
TOTAL FINANCIAL CONTRIBUTION TO HOUSEHOLD:		
R500 or less	46	56%
>R500-R1500	25	30%
>R1500-R2500	4	5%
>R2500	6	7%
Missing data:	1	2%
PREVIOUS EMPLOYMENT:		
DOMESTIC /FACTORY/BLUE COLLAR	28	34%
HOMECARE/CHILDCARE	5	6%
UNEMPLOYED/ STUDENT/SCHOOL	8	10%
NURSING	6	7%
OTHER	34	41%
Missing data:	1	2%

3.7 Research Tools:

A self-report questionnaire including two parts was administered to the participants. The first part consisted of biographical/demographic information of the respondent. The second part covered the Ways of Coping Questionnaire (WCQ) (Lazarus & Folkman, 1988). The WCQ, developed by Lazarus and Folkman (1988), is designed to measure the thoughts and actions used by individuals to cope with specific stressful encounters. The authors note that studies show that people use both emotion and problem-focused coping in almost every stressful encounter, hence the need to assess both functions.

The 66 item scale consists of the following eight sub-scales:

1. Confrontive Coping - aggressive efforts to change the situation and suggests some degree of hostility and risk taking.
2. Distancing - cognitive attempts to detach oneself and to minimize the significance of the situation.
3. Self-Controlling - efforts to regulate feelings and actions.
4. Seeking Social Support - efforts to seek informational, tangible and emotional support.
5. Accepting Responsibility - acknowledges the individual's own role in the problem as well as attempts to put things right.
6. Escape-Avoidance - wishful thinking and behavioural efforts to avoid the problem.

7. Planful Problem Solving – deliberate, problem-focused efforts to change the situation, as well as an analytic approach to solving the problem.
8. Positive Reappraisal - the efforts to create positive meaning by focusing on personal growth (Lazarus & Folkman, 1988).

Responses to each item are presented on a 4-point Likert scale indicating the frequency with which each strategy is used ranging from zero for "does not apply" or "not used", to three for "used a great deal".

The participant is asked to think about the most stressful experience that occurred during the past week. No single standardization method has been designed for eliciting the event, hence the method used must be adapted to fit the needs of the study (for the purposes of this study, an experience related specifically to their work with HIV/AIDS patients was requested).

The WCQ is self-administered and takes approximately 10-20 minutes to complete. An interview can be held to assist the participant to reconstruct the focal encounter and to check that all items are responded to after the inventory is completed. A comparison of responses showed no change to the amount of problem-focused coping reported, but that there was an increase in the amount of emotion-focused coping reported when an interviewer was present (Lazarus & Folkman, 1988).

The WCQ has been tested with regard to reliability and internal consistencies. The Cronbach's coefficient alpha for the eight scales ranged between 0.61 and 0.79 in a study done by Lazarus and Folkman (1988) during the development of the scale. They administered the scale to 75 middle to upper class white married couples who had a minimum of one child. Both partners were interviewed monthly over a five month period. The questionnaire items were analyzed using alpha and principal factoring with oblique rotation.

Three different factor analyses were conducted applying different strategies for combining person-occasions or observation. This involved first, analysing 750 observations from 150 participants on each of the five occasions on different stressful encounters. Second, one stressful encounter for each 150 randomly selected subjects from the 750 observations with each of the five occasions equally represented, is selected. Third, completing an additional procedure without replacement of the prior 150 encounters, and equally representing each of the 5 occasions. The three yielded similar factor patterns, and the final analysis of the consistently loaded items on the same factors yielded eight factors that resulted in eight subscales (see Table 4). The scale has face validity as the strategies described in the items reflect those used by the individuals in the above noted study to cope with stressful situations.

Table 4

Psychometric Properties of Coping Scales: Averaged over five occasions (n=150) (Taken from Lazarus and Folkman, 1989, p.9)

Scale	No. of items	Mean	SD	Skewness	Alpha
1. Confrontive Coping	6	3.94	2.09	5.47	.70
2. Distancing	6	3.05	1.78	1.10	.61
3. Self-Controlling	7	5.77	2.87	.46	.70
4. Seeking Social Support	6	5.40	2.40	.60	.76
5. Accepting Responsibility	4	1.87	1.44	.99	.66
6. Escape-Avoidance	8	3.18	2.48	1.20	.72
7. Planful Problem Solving	6	7.25	2.34	.10	.68
8. Positive Reappraisal	7	3.48	2.98	1.25	.79

Clark, Bormann, Cropanzan and James (1995) used the WCQ on a sample of 306 students from an introductory psychology class and noted that results of confirmatory factor analyses fitted their data reasonably well. The WCQ has also been reliably used to assess coping amongst nurses (Bennett & Kelhar, 1993).

Stone, Greenberg, Kennedy-Moore and Newman (1991) conducted a study using the WCQ to investigate the nature of measurement of self-report, situation-specific coping questionnaires. They identified several potential issues in the development of the questionnaire. The fact that certain of coping items used are not always applicable to different kinds of stressful encounters; that the definition of the period for which coping is reported varies; and the variability in the meaning of the "extent" response key that is used for reporting coping items. The study was done on 91 college students and the results supported hypothesized concerns that many of the items were not applicable to certain stressful events, that the coping period defined varied for subjects and that the extent response key interpretations differed. In order to make results easier to interpret, they suggest using a single response key, and that the coping stage at which the subject is at should be defined and that the applicability of items to particular problems (e.g. interpersonal, health problems, work problems) be assessed.

3.8 The use of the WCQ in a cross-cultural context

Researchers using the WCQ in cross-cultural contexts have noted certain difficulties in its applicability to samples that differ from the original American sample on which it was based.

Bramsen, Bleiker, Triemstra, van Rossum and van der Ploeg (1995) investigated the factor structure and psychometric properties of a Dutch adaptation of the WCQ. In an exploratory factor analysis six scales were constructed, five of which had many items in common with the corresponding original scales. From the original scales Self–Controlling and Confrontive Coping had no Dutch counterparts. Internal consistency, test-retest reliability and concurrent validity showed favorable results (Bramsen et al., 1995).

In South Africa the WCQ has been used to assess coping strategies amongst teachers in a school setting (Florence, 1998). She reported a lower alpha coefficient on most of the scales compared to those reported by Lazarus and Folkman (1988). Internal consistency for the original sample was higher (.61 to .79) than the coefficients for her sample (.38 to .76). Respondents were noted as scoring consistently higher on the coping scales than the original sample. Five of the coping subscales were excluded from the final analysis due to their low reliability. They were Confrontive Coping, Distancing, Self-controlling, Accepting Responsibility and Planful Problem Solving. Face validity and construct validity were both noted as acceptable by Florence (1998). The researcher is not aware of any further studies done with this scale on a South African sample.

Smyth and Yarandi (1996) studied the factor analysis of the WCQ for African-American women. Their sample of 656 women ranged in age from 22 to 64 years, all were employed, with a mean annual income of $24,300. The researchers were interested in the influence of cultural and social variables in the coping process. When compared to the sample used by Lazarus and Folkman (1980) factors highlighted below, emerged suggesting a need for a possible revision of the instrument or the development of a new one (Smyth & Yarandi,1996).

An exploratory principal factor analysis with the square multiple correlation in the main diagonal of the correlation matrix produced three factors; Active Coping, Avoidance and Minimize the Situation (Smyth & Yarandi,1996). These factors explained 67% of the total variance as compared to 46.2% explained by the eight factors investigated by Lazarus and Folkman (1980). On the basis of a .40 criterion for factor loading 35 of the original 66 items were retained. The alpha coefficients for the remaining factors ranged from .76 to .84.

The first factor, Active Coping, revealed that subjects selected strategies involving talking to others to cope (Smyth & Yarandi,1996). Smyth and Yarandi (1996) discuss the use of this means of coping in terms of African American values of interdependence, co-operation and mutual respect within extended family networks. They comment that even though women experience stress and conflict in their multiple roles, social support networks of family, friends and clergy provided much needed support. With regards to Avoidance Coping, they note that this could be viewed as an undesirable coping strategy, but in situations where minorities have a lower sense of control, possibly due to blocked opportunities in White-dominated economies, such a strategy may be highly effective when confronted with stress that can't be resolved using Problem-Solving (Smyth & Yarandi,1996). They also note that the appropriateness of a way of coping is task dependent and that situational and personal factors interact to determine how a person then copes. Measurement of coping strategies therefore reflects interaction with other factors. The factors identified in the WCQ do not necessarily describe how these African American women cope with stress. Given that only 35 items loaded on a three-factor model, lead the researchers to suggest that the remaining 31 items be re-examined for elimination. They further recommend that a new self-report questionnaire be developed to accurately identify coping strategies used by African Americans (Smyth & Yarandi,1996). The researcher was unable to find a re-developed scale for the purposes of this pilot study.

3.9 Additional qualitative information

The researcher added a third part to the WCQ, which consisted of two open-ended questions, requesting participants' views on how they cope with their work and what they feel would help them to cope more effectively. These questions aimed to try and identify other influencing factors on coping styles adopted (excluding the biographical variables). Participants were assured of confidentiality, as it was felt that this would facilitate them being able to express their views with honesty. The researcher also obtained observational data to further contextualise the information obtained in the study by visiting the three of participating organisations, discussing the difficulties being experienced by caregivers with co-ordinators, and accompanying a group of caregivers on one occasion on their home visits.

Given that this part of the study falls within a qualitative framework, it is acknowledged that research results generated from these questions are characterised by indexicality, inconcludability, subjectivity, and reflexivity (Banister, Burman, Parker, Taylor, & Tindall, 1994). The meanings generated are specific, or indexical to the specific research event. In a different setting with different subjects, alternative meanings may have emerged. Inconcludability refers to the fact that the results may be conclusive and generalisable, but could reflect the feelings of the particular caregivers within a particular socio-cultural context (Pecego, 1995).

Qualitative research acknowledges that an objective account of phenomena is arrived at through an exploration of the way in which the subjectivity of the researcher structures the way the account is defined (Banister et al., 1994). The researcher acknowledges her positioned subjectivity as a 31 year-old, White, female, English speaking Masters student conducting research for her thesis. Her own cultural background, home language and education, conceptions of what it means to cope and what one finds particularly stressful have been informed by her own life experiences. It is on the basis of this understanding that the research was conceptualized. It is acknowledged that these experiences in many ways are vastly different from the caregivers that participated in this study. Her own expectations about the way in which people would be able to comment on their experiences i.e. in a research questionnaire, encompass her own assumptions about how one would feel comfortable to express information about how they cope. There is also an assumption that there is a shared meaning with regards to the questions posed in the study and that what has been researched is of cultural relevance for these participants. Reflexivity refers to the researchers' acknowledgement of the relinquishment of neutrality in favor of an effort to monitor how her own subjectivity structured the research process and analysis of the questions. What caregivers noted as stressful and how they coped was interpreted through the researchers own understanding of these experiences. Reflexivity also entailed taking into account feedback from the co-ordinators about difficulties experienced with the administration of the questionnaire.

3.10 Procedure:

The researcher made personal contact with co-ordinators from the four organisations that participated in the present study, in order to explain the purpose of the research and to request permission to conduct the research in these organisations. The questionnaires were distributed to the participating organisations by the researcher from July to August 2001. The researcher and key members of the participating organisations were then available to facilitate their completion process and answer questions if necessary. After the study had been introduced and explained by the co-ordinators, the caregivers were asked for informed consent to participate in the study.

The questionnaire was translated into predominant languages used by the caregivers (Afrikaans and Xhosa), to facilitate participation by the respondents in their first language. Brislin, Lonner and Thorndike (1973) note that unless empirical evidence of the equivalence of different-language versions of the same instrument is presented, translation difficulties could account for plausible rival hypotheses for any results obtained. Wording problems can often occur as translations are influenced by the specific frame of reference of the person posing the question (Brislin, Lonner & Thorndike,1973). They recommend pre-testing of items even after careful translation to assist with ensuring translation quality and equivalence of source. The accuracy of the translation of the WCQ for this study was checked via back translation. Translators were briefed by the researcher about the nature of the study and the expected level of education of the participants. The researcher erroneously did not review the English versions of the back translations with the questionnaires. The accuracy of the translations was confirmed by bilingual translators who assisted with the study.

The results revealed that there may have been difficulties with the meaning and level of translation of the WCQ. This is possible given that the level of education and sophistication of language use of the translators was generally higher than the participants. This was raised in feedback obtained after the data had been collected from the Caring Network specifically regarding the Xhosa version of the WCQ. The Afrikaans version may have had similar difficulties given the overall findings of the study, but this was not specifically raised by participants or investigated by the researcher. This indicated that the translations needed to have been checked before administration by individuals who were more representative of the participants. Given that this was a pilot study, the translation issues raised in the feedback, highlight the need for them to be considered for further research in this field.

3.11 Data Analysis:

The data was analysed using the SPSS statistical package. Firstly, an analysis was done of the psychometric properties of the WCQ. This analysis yielded descriptive statistics for each of the different eight coping strategy scales in the form of means and standard deviations. It also yielded alpha coefficients that indicated the reliability of each of eight scales. Secondly, correlations between the eight scales were computed. These scores were compared to the normative sample on which the scale was devised using the psychometric properties shown in Table 4 to determine if it functions similarly for this group of participants. This was done using Pearsons Product Moment Correlation's. On the basis of the correlation scores, principal components analysis was used to investigate the dimensionality of the WCQ scales.

Due to the fact that this was a pilot study, 27 questionnaires (33% of the sample) were selected by the researcher on a convenience basis to provide a context for the quantitative findings. A formal qualitative analysis was not attempted and the findings must be interpreted with caution as they are not necessarily representative of the participants from the study, rather they yield interesting considerations for work in this area. The method of presentation of these findings was adapted from an approach recommended by Morgan (1988) involving the inclusion of themes and direct quotations, rather than one of these methods to provide additional reinforcement to research findings.

3.12 Ethical Considerations:

Informed consent was obtained from the participants and their participation was voluntary. Participants were assured that their responses would be confidential and that the questionnaire was anonymous. At the end of the study, copies of the mini-thesis will be made available to the various care organisations involved, as well as feedback provided by the researcher on the results.

3.13 Chapter Summary

This chapter outlined the methodology used in the study. Specifically the participants, the research design, the research tools, the procedures used, and the method of data analysis. Ethical considerations were also discussed.

CHAPTER 4

RESULTS

4.0 Introduction

This chapter provides a report of the psychometric properties for the Ways of Coping Questionnaire for a group of home-based caregivers within the South African HIV/AIDS home-based care context. The chapter also presents the correlation of the WCQ subscales and compares them to the normative American sample from which they were derived. On the basis of the above results the data was reduced using principal component analysis to describe and summarize the data and compare it to the original scale. Results detailed from the investigations noted lead to the presentation of a rationale for not examining the relationship between demographic variables (age, gender, financial status, and education) and the scores on the Ways of Coping Questionnaire for the home-based caregivers.

Finally, current sources of occupational stress for the participating home-based caregivers and factors that they perceive as being able to assist them to cope better with these stressors were qualitatively identified from a conveniently selected group of the participants to provide a context for quantitative results. Observational data collected by the researcher will also be presented to further contextualise results.

4.1 Quantitative Data

The following section presents descriptive statistics and reliability indices.

Table 5 details the means, standard deviations and Alpha coefficients calculated from the data collected in the present study.

Table 5

Description of 8 Factor Means: Confrontive Coping, Distancing, Self - Controlling, Seeking Social Support, Accepting Responsibility, Escape Avoidance, Planful Problem Solving and Positive Reappraisal scores obtained from the WCQ scales

Factor	N Statistic	Mean	Std. Deviation	Alpha
Confrontive Coping	73	1.7877	.5626	.47
Distancing	76	2.0197	.6206	.73
Self Controlling	72	2.0119	.5152	.54
Seeking Social Support	76	2.2632	.6002	.61
Accepting Responsibility	74	1.8345	.7111	.64
Escape – Avoidance	69	1.7428	.5050	.36
Planful Problem Solving	73	2.2329	.5006	.63
Positive Reappraisal	65	2.3846	.4968	.64

Note: Totals of N are not equal to 82, as some participants did not complete all the data

The mean scores for the use of the eight coping strategies of the WCQ, as recorded from the 4-point Likert scale used by Lazarus and Folkman (1989) ranging from zero for “does not apply” or “not used”, to three for “used a great deal”, in Table 5. fall between 1.7 and 2.3 indicating that most strategies were recorded as being used “quite a bit” which is scored as two on the scale.

Estimates of internal consistency (Chronbach’s alpha coefficient) using a minimum reliability of 0 .7 as detailed in Table 5. , revealed that seven of the eight scales produced less than satisfactory reliability scores. Distancing which had an Alpha score of .73 , was the only scale that indicated that the data obtained was reliable. When compared to reported alpha coefficients by Lazarus and Folkman (1989) in Table 4, it is evident that internal consistency for the original sample was higher ranging from .61 to .79 as opposed to the coefficients from this sample which ranged from .36 to .74. Participants from the present study scored higher on the coping scales than the original sample.

Low reliability scores may have been attributed to ambiguous translation of questionnaire items, the lack of applicability of the scale in this cultural context, and the inaccessibility of the level of translation in view of participant’s level of education. These low reliability scores lead one to interpret all the following results cautiously. Any observed relationship between demographic variables and the WCQ scores would be attenuated due to the insufficient reliability of the WCQ scores for this group of participants.

4.1.1 Correlation of WCQ Scales:

Results from the analysis of the correlation of the WCQ scales from this study indicate that the scales from the South African sample used in this study correlate much higher than in the normative American sample. The average correlation for the American sample is 0.24 as detailed in Table 6 compared to the average for the South African sample used in this study is 0.60 as detailed in Table 7.

Table 6: Intercorrelation of Coping scales: American Sample

Scale	1	2	3	4	5	6	7	8
1. Confrontive Coping		.01	.36	.27	.26	.27	.28	.26
2. Distancing			.36	-.04	.27	.32	.09	.13
3. Self-Controlling				.24	.30	.36	.37	.39
4. Seeking Social Support					.09	.23	.30	.32
5. Accepting Responsibility						.39	.13	.18
6. Escape Avoidance							.10	.23
7. Planful Problem Solving								.39
8. Positive Reappraisal								

Total Average Correlation = 0.24

The correlation scores of the scales for the present study overlap to a greater extent than the original sample and this is evidenced by the on average higher individual correlation scores as displayed in Table 7 when compared to the individual correlation scores in Table 6. This reveals that individuals appear to have responded similarly to items within different subscales for the present study. The scale therefore appears to be unsuitable for this population and results indicate that participants may not have understood the questionnaire items or the items were not relevant to their experiences.

Table 7: Intercorrelation of Coping scales: Present study

Scale	1	2	3	4	5	6	7	8
1. Confrontive Coping		.60	.41	.41	.46	.51	.38	.63
2. Distancing			.55	.44	.61	.43	.59	.55
3. Self-Controlling				.50	.45	.48	.58	.56
4. Seeking Social Support					.39	.30	.67	.68
5. Accepting Responsibility						.43	.67	.50
6. Escape Avoidance							.42	.28
7. Planful Problem Solving								.77
8. Positive Reappraisal								

Total Average Correlation = 0.60

4.1.2 Data Reduction:

Due to the overlap of meaning as indicated by the high correlation between the subscales in the present study, it was decided to reduce the data to the two categories suggested by Lazarus and Folkman i.e. emotion and problem-focused coping. The correlation between the scores for the categories of emotion and problem-focused coping was computed revealing a high correlation of 0.85, suggesting an overlap 72% of the variance of scores for the two categories are shared - see Table 8.

Table 8: Intercorrelation of Problem and Emotion Focused Coping

Scale:	Emotion Focused Coping	Problem Focused Coping
Emotion Focused Coping	1.0	.85
Problem Focused Coping	.85	1.0

This suggested that the data might be further reduced to a single category. A principal components analysis of the eight WCQ scales supported the reduction of the data to a single category. The loading of the eight scales as detailed in Table 9, on the first unrotated factor were all higher than .70 and the component explained 61% of the variance of the eight scales.

Table 9: Component Matrix: Principal Component Analysis

1. Confrontive Coping	.70
2. Distancing	.78
3. Self-Controlling	.76
4. Seeking Social Support	.80
5. Accepting Responsibility	.83
6. Escape Avoidance	.70
7. Planful Problem Solving	.86
8. Positive Reappraisal	.82

On the basis of these findings it was apparent that the eight WCQ scores could be reduced to a single coping score. Such a score does however not provide meaningful information. The large degree of overlap found in the WCQ scales cast doubt as to the independence of the scores obtained in this study. The quantitative analysis of the data has therefore revealed that the scales are not functioning as they should, and it is further concluded that it would not be useful to do additional comparisons of the relationship of the eight subscales with the demographic variables, as any relationships found would be weakened by the unreliability of the scales.

4.3 Qualitative data

Twenty-seven of the participants' responses to the two open-ended questions were conveniently selected and analysed impressionistically by the researcher. The analysis yielded several relevant comments for consideration concerning their current stressors, coping strategies and coping needs at present. These comments allowed for a greater contextualisation of the study and an understanding of some of the difficulties that these selected caregivers were coping with, and which were not adequately revealed due to the unreliability of the quantitative scale used for the group of participants. They included possible interventions that could be used to assist carers with their present work, as well as the factors that are currently hindering them.

Out of the responses reviewed, the majority of caregivers felt that the most stressful aspect of their work was the pain they felt as a result of being exposed to human suffering on a daily basis. HIV/AIDS care often involves an extended period of involvement with the patient and their family in the intimate context of their own home. A caregiver stated:

> "As die mense baie siek word. As hulle huil van pyn"
>
> This was echoed by another who said "When I see them suffering like this I feel bad as if I am the one who is suffering."

Another caregiver said:

> "om die mense te sien die dood in die oë".

Certain of the caregivers felt that people's attitude towards AIDS and the patients as well as caregivers' exposure to societal discrimination and stigmatisation made the work particularly hard, especially in comparison to the treatment of other terminal illnesses. This view was reflected in this caregivers response:

> "Members of the society treat AIDS sufferers like outcasts. I also worry about my own safety. Sometimes the family of the patients tend to involve me in matters, which do not concern me. They sometimes insult the patient in my presence. These are the problems that I experience in this job."

There were caregivers that felt that the extreme poverty and the lack of food in many of the homes of the sick people that they visited, as well as the inaccessibility of hospital and professional medical support, were some of the biggest stressors they faced. The difficulty coping with the stress of poverty was a pressing concern of many of the caregivers.

One expressed that:

> "Some patients are starving and exposed to cold. In such circumstances they lose hope. It is painful to be unable to help a patient who is in such a condition."

Another caregiver said:

> "I also wish that they would get good food so as to be in good health. Their health deteriorates when they have nothing to eat. We request that they be given good treatment. May the government discover the AIDS cure very soon."

These circumstances make it difficult for caregivers to cope, specifically they evoke feelings of helplessness, especially in the face of exposure to many patients dying. Many of the twenty-seven caregivers reviewed reflected on their feelings of helplessness and the realisation of the limitations of their efforts in the face of this epidemic. A caregiver reported that:

> "seker die feit dat 'n mens soms so hulpeloos voel, omdat jy niks meer vir die wat al so siek is kan doen nie, of vir hul kinders nie".

With regards to how the reviewed group of caregivers said they coped with their work stress, the majority of the caregivers relied on their faith, tried to control their feelings, turned to informal support from colleagues and family. One caregiver said:

> "It helps to do this job with my colleagues; otherwise I am unable to do it alone".

Another noted that:

> "I pray before I set out to see my patient." The emotional stress does however at times overwhelm caregivers, "these conditions are very stressful, and sometimes we simply burst into tears".

Regarding what these caregivers thought would assist them cope better with their work, certain caregivers expressed a need for continued training and support groups, as well as financial support and necessary equipment/food and places of safety where HIV/AIDS patients can receive care without discrimination. A caregiver stated:

> "You have to get counseling so as to be able to speak when you come from your patient. "

There was an expression of concern for the health risk of infection as a result of their work. This was highlighted by the request of a caregiver :

> "We need to be protected from contracting AIDS."

This selected group of caregivers also noted a need for recognition and support, from the state in addition to informal support systems that they currently utilize. One caregiver requested that:

> "Caregivers should not join the queues, and welfare grants for AIDS suffers (sic) must not be terminated."

They also highlighted the need for greater access to resources. A caregiver stated:

> "I need to have equipment such as a wheel chair." While another caregiver felt that "they need to be accommodated in hospitals where we can get their medicine and help them."

While another caregiver noted that:

> "I think there is a need for a place where all AIDS suffers (sic) would stay. We can provide better care if they all stay together."

4.4 Observational Data

The researcher accompanied certain of the participants in the study on home visits to gain an understanding of the living conditions of the patients they treat and the circumstances under which they work. Her impressions were that the overwhelming levels of poverty make it impossible to address issues of care and caregiver coping in the South African context without viewing the work being done within a context of starvation, poor sanitation and limited access to hospital care. The researcher was also struck by the incredible dedication and commitment shown by caregivers who were often receiving minimal or no financial gain from their work.

4.5 Chapter Summary

The results revealed that there was a large degree of overlap found in the WCQ scales indicating a lack of independence of the scores obtained in this study. This reveals that individuals appear to have responded similarly to items within different subscales for the present study. The scale therefore appears to be unsuitable for this population and results indicate that participants may not have understood the questionnaire items or the items were not relevant to their experiences. It was therefore concluded that the WCQ was not functioning as it should, and it was therefore not useful to do additional comparisons of the relationship of the eight subscales with the demographic variables, as any relationships found would be weakened by the unreliability of the scales.

Contextual information was gleaned from a review of a convenience sample of written responses to the questions exploring individual caregivers' own perceptions of coping strategies, stressors and possible aids to improve coping and observational data collected by the researcher. The review indicated that the selected group of caregivers identified specific issues that were stressful regarding their work and that they were coping with them in a variety of ways. They indicated that poverty, lack of medical resources, coping with helplessness and death were frequent stressors. These caregivers noted that they used their faith, support from family and colleagues and controlling of their emotions as ways of coping. They felt that additional training and support groups, government support, places of safety for PWAs and equipment/food would assist them to cope better with the demands of their work. The discussion of these results is detailed in the following chapter.

CHAPTER 5

DISCUSSION, RECOMMENDATIONS AND CONCLUSIONS

5.0 Introduction

This chapter details a discussion of the results from the present study in light certain limitations that emerged from the analysis of the data. It also provides possible explanations for the major findings reported in the previous chapter as well as stating recommendations for future studies.

5.1 Limitations of the present study

In light of the results revealing that the scale was unsuitable for this population and that participants may not have understood the questionnaire items or the items were not relevant to their experiences, certain limitations of the present study need to be considered in a discussion of the findings and the contribution of this study to existing research in this area. They also highlight the need for caution in the interpretation of subsequent results from the analysis.

Concerns raised by Smyth and Yarandi (1996) regarding the WCQ's applicability for African American women and more generally its applicability in a cross-cultural, cross-linguistic context bear certain resemblance to the findings of this pilot study The applicability of this research instrument in the South African context needs to be considered in light of the alpha coefficient scores from this study which ranged from .36 to .74.

This study highlights the need to consider the cultural equivalence of concepts measured by scales devised on population groups that are distinctly different to the population used in this study. Further, embarking on a process of translation and back translation can lead one into the danger of results seemingly being taken to reflect or not reflect existing theory, when in fact they may merely reflect poor translation of questionnaires and research instructions (Brislin, Lonner & Thorndike,1973).

Feedback received from a trainer who helped administer the questionnaire at the Caring Network seemed to point to the fact that the Xhosa translation of the WCQ in this study presented with such difficulties to participants. She felt that due to the limited education of many of the carers, and given that it was their first experience of filling in a questionnaire, they struggled to complete it. She assisted them and it took groups of approximately 10 - 15 carers between 1.5 hrs – 2hrs to complete the forms. The increased time taken by these participants indicates the possible extent of the inapplicability of the WCQ in this context as Lazarus and Folkman (1988) recommend self-administration taking 10-20 minutes. She also noted that certain questions were repetitive, some inappropriate and that the fine print was difficult to read. She felt that all the carers were willing to complete the questionnaire because they trusted her and because they remembered the researcher who had attended a monthly support meeting prior to administration of the questionnaire. Perhaps they valued the involvement of the researcher, as it might have made them feel that they were not just objects in a study. She also noted that the level of Xhosa used in the translation was often hard to understand.

Further relevant concerns about the applicability of the WCQ in the South African HIV/AIDS context were raised by a caregiver from the fifth organisation, Joy for Life, approached for the study and detail why this organisation was unwilling to participate. The caregiver, a 45 year old male who had been providing care to between 3 and 20 people at any one time and who had been doing this work for 15 years, stated that "the questions were inappropriate and one - sided". He felt "the questionnaire was one-sided, that it makes me feel like I'm not coping". He added that " patients may feel they can't cope, but if he couldn't cope he wouldn't do this work". He felt that the demographics were also not suitable, that education would not make one cope, but that life experience, emotional and psychological criteria were more important in the assessment of one's coping ability. He also noted that the stage of illness that patients are at is important information to note as it impacts upon the demands placed on the caregiver and that the number of patients in care did not accurately reflect what level of care was being provided. He also added that he did not find the work difficult, and that "my view of death doesn't make it difficult".

Concerns raised by the carer from Joy for Life were also raised by other researchers, Stone et al. (1991) as well as Smyth and Yarandi (1996) regarding the use of the WCQ -when researching a specific subject. They all note its limitation as an AIDS care evaluation instrument due to its generic nature, with many questions not necessarily being relevant.

Without knowing the specific encounter on which participants based their responses to the WCQ, the researcher has no way of knowing if the questions asked were applicable. It is not possible to confirm the appropriateness of the questions posed. This also prevented a full understanding of the meaning of a zero score on the instrument. The questionnaire's design results in a response of "not applicable" being conflated with "not used", thereby limiting what can be interpreted from the responses

The above limitations support recommendations made by Lazarus and Folkman (1988) who recommend using an interview to assist the participant to reconstruct the focal encounter, and that this inclusion influences the type of coping responses elicited from the questionnaire. The failure to clarify the focal encounter on which the respondents completed the WCQ is acknowledged as a critical shortcoming in the administration of this research.

Stone, Greenberg, Kennedy-Moore and Newman (1981) also highlighted similar potential issues raised above concerning the development of the questionnaire. They comment on the non-applicability of certain items, the variability of meaning in responses and the participants results being unclear in light of them not clearly defining the encounter used. They also recommend making changes to the design of the instrument.

A further limitation of the present study relates to the different levels of involvement of the four organisations in assisting their caregivers with the completion of the questionnaire. The impact of this could be the reason for the vastly different response rates between the participating organisations. It is acknowledged that this inconsistency could have confounded results and caregiver motivation for participating in the study.

Had all the existing methodological problems not have arisen with the WCQ, it would be suggested that the instrument be standardized for the South African population, and that a larger more equivalent sample size be compared to the original study used. However in light of the limitations raised, the researcher does not recommend this as an area of further research.

Furthermore, it is possible that a formal qualitative analysis of the two open-ended questions added by the researcher could potentially provide a greater understanding of the coping strategies used by caregivers in this study. Based on feedback from Joy for Life it is suggested that additional questions could enhance knowledge about other factors that impact on the coping strategies used by caregivers. The present study attempted to investigate the influence of certain demographic variables on the coping strategies used by caregivers. The influence of these as well as additional factors such as life experience, previous experiences of loss and illness, attitudes towards death and dying, belief about HIV/AIDS, intra-psychic and organisational variables that are believed to impact on an individual's appraisal of their work as a home-based carer would be of interest in further studies. Finally, the study did not investigate what caregivers enjoyed about their work, and what made them resilient. This would also be useful with respect to the development of supportive interventions and training programmes for caregivers.

5.2 Explanation of main findings

In view of the limitations above and the impact that they have on the ability to generate meaningful findings from the present study, a discussion of the findings is presented. The main aim of the present study was to provide descriptive statistics for the WCQ for a group of caregivers providing home-based care for people with advanced HIV/AIDS infection within the South African home-based care context. Seven of the eight subscales of the WCQ generated unreliable results. It was found that caregivers significantly used both emotion and problem-focused coping skills to deal with the stress they encountered during the provision of home-based care for PWAs. These categories were shown to have a high enough correlation (.85) which lead to them being reduced to a single category. A discussion of the distinction between emotion-focused coping and problem-focused coping was thus not meaningful for this study. A review of the relationship of demographic variables and coping strategies was unable to yield any results as this analysis was not suitable given the unreliability of the WCQ subscale scores

Qualitative comments noted by the caregivers conveniently selected to provide additional contextual information for the present study included requests for further training to assist them to cope better with their work. Further training could provide caregivers with additional information and skills to enable them to find solutions to more of the problems they encounter with their work. This finding compares with studies done by Barbour (1994) and Bennett et al. (1991) who noted that training influences ones' vulnerability to psychological distress in AIDS related work. Dreidger and Cox (1991) also noted that nurses caring for PWAs levels of experience affected their levels of emotional exhaustion. In a context where many of the caregivers have received limited training and education, this has serious implications for the possible longer-term effects of providing this service. While continued work is likely to increase their experience, the provision of supportive training can enable improved coping. It is hypothesized that additional training could serve as a possible distress reduction factor to enhance caregiver coping for PWA's in South Africa today.

Qualitative comments by the selected participants also mention the difficulty of societal discrimination and stigmatisation involved in the care of PWA. This highlights the need to increase public awareness and tolerance of HIV/AIDS as this could possibly enable caregivers to cope more effectively with their work. Much of the AIDS care literature focuses on studies done with nurses (Bennett, Michie & Kippax, 1991; Bennett, Kelhar & Ross, 1994; Driedger & Cox, 1991; Sherman, 1996). Many of the challenges of caring for PWAs as seen in the qualitative comments noted by the selected home-based caregivers in this study confirm challenges identified by nurses abroad. These include dealing with death and loss, the use of informal support from colleagues and fear of infection. They are also confirmed in findings of Catalan et al. (1996), Horsman and Sheeran (1995) and Klonoff and Ewers (1990).

When comparing research done abroad on HIV/AIDS it is clear that there are also certain distinctive issues that are specific to AIDS care in South Africa. These are linked to the socio-economic reality currently faced by many caregivers and PWAs: that is a socio-political context marked by oppression and discrimination from which public health policy and practice has historically emerged. Some caregivers noted concerns about this reality in their qualitative comments. The issue of poverty increases caregivers' and PWAs' vulnerability to stress and this in turn impacts upon their ability to cope with their current circumstances.

The results of the study were unable to reveal the specific impact of socio-economic circumstances on the caregivers' coping. Demographic information does however show that the majority of monthly incomes and household finances fall at or below R1500 per month. These findings and observations made by the researcher alert one to need to investigate the impact of poverty on the types of coping strategies used specifically by individuals in the South African context. Given the paucity of research focusing specifically on coping within this population, and the fact that many studies in the literature investigate burnout, it is difficult to draw comparative conclusions in relation to past research. Understanding the impact of AIDS in the South African context and its implications for care requires a cultural as well as a biomedical understanding.

Barbour (1994) and Florence (1998), found age or gender to be a significant variable in their investigation of coping. This study was not able to investigate the significance of these variables given the unreliability of the results, the limited number of male participants and the predominance of female home-based carers in South Africa to date.

The majority of the caregivers participating in this study had only been providing care for between 0-3yrs. Researchers would need to conduct a longitudinal study to accurately comment on turnover rates and burnout noted in other studies (Bennett, Kelhar & Ross, 1994; Bennett, Michie & Kippax, 1991).

5.4 Recommendations for future research

The limitations raised by this study regarding the difficulty of applying the WCQ to a variety of coping situations, its standardization on a specific population different from the one in this study, in a different language to that used by these participants, prevented the WCQ being established as a culturally equivalent and relevant research instrument. Further, the unreliability of scores obtained in addition to the limitations noted above provides ample evidence to support the claim that the WCQ is an inappropriate instrument for the study of caregiver coping in the South African HIV/AIDS home-based care context. It is therefore recommended that the development of an alternative research instrument be considered in light of these limitations.

Given the unreliability of the WCQ scales, the demographic variables were unable to produce a statistically meaningful relationship to coping strategies used by caregivers. It is suggested that focus groups in the home language of caregivers be conducted to obtain contextual information regarding emotional and psychological criteria, life experiences, stage of illness of PWAs being cared for, and an understanding of the positive and negative aspects of the work being done. A qualitative (discourse-analytic) study could lend itself to gaining a deeper understanding of the personal meaning of coping for home-based caregivers. The contextual information gleaned from such qualitative research methods could then be used to guide the development of a more suitable quantitative research instrument for this area of study.

The WCQ might have provided more meaningful information if an inclusion of the respondent's description of the event used when completing the questionnaire was supplied. In addition, if a pilot study of the questionnaire had been done on respondents similar to those participating in the study this may have helped to establish greater cultural relevancy and equivalence. The results would also need to be compared to those obtained from, the standardisation of WCQ for the South African population. The inclusion of the focal encounter and comparing results to South African norms are important points to note for further quantitative research using the WCQ or any other instrument. Data from this study could also be used as a means of comparison for further studies in this area.

Finally it would also be of interest to investigate the relationship between burnout and coping strategies used by caregivers for PWAs, to determine more closely the effectiveness of specific coping strategies in the face of stress.

It is difficult given the problems with the WCQ to recommend useful interventions. The following speculations have been put forward on the basis of information obtained from the twenty-seven convenience sub-sample drawn from the participants. Additional support groups and training for caregivers might assist them to continue to cope with the work they do. Such training could focus on bereavement counseling, de-briefing for caregivers themselves, and training caregivers as peer supervisors and support group facilitators.

Obtaining information from the other participating organisations might enable caregivers to gain a sense of shared experiences and understanding of their difficulties as well as their resilient responses to these difficulties.

5.5 Conclusions

The main aim of this study was to provide descriptive statistics for the Ways of Coping questionnaire for a group of home-based caregivers for people with advanced HIV/AIDS in the South African home-based care context. Secondary aims included determining the relationship between specific demographic variables and the coping strategies employed by carers. The study also sought to understand what caregivers found difficult about their present work, how they were coping and what they felt could assist them to cope better in the future. Results indicated an insufficient reliability of scores to deduce meaningful observed relationships between the scales themselves and the demographic variables obtained.

This study was conducted within a context of poverty, limited financial resources and an illness that has reached epidemic proportions. HIV/AIDS within the South African development context and the government's current attitude to the national crisis is further compounded by the legacy of apartheid. We can predict with certainty that patient loads will grow in the future and that coping is not a static phenomenon. Thus well-considered interventions at multiple levels of society are needed to address patient and caregiver needs. It is hoped that the findings of this study and future studies can be used to guide researchers to conduct reliable and meaningful exploration of this important area of health research in South Africa.

It is also hoped that information regarding the needs and stresses experienced by home-based caregivers can be used to increase government awareness of the needs of home-based caregivers and inform recommendations for further resource allocation needed to sustain on-going home-based care for those suffering from HIV/AIDS related illnesses. It is apparent that caregivers are providing an invaluable service to those in need. It is also clear that the stress inherent in their work, makes them vulnerable to burnout, and ensuring that they are able to cope is vital.

The results of this study highlight the need to develop more appropriate quantitative measures for cross-cultural and cross-linguistic research that wants to understand caregiver coping within the South African HIV/AIDS context.

It also demonstrates that research using unreliable and inappropriate research instrumentation is unable to provide meaningful and reliable commentary on the area of research on which it focuses. Research in the South African context and specifically in the South African HIV/AIDS context needs to take into account the variety of linguistic and cultural nuances inherent in this field.

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APPENDIX A

THE WAYS OF COPING QUESTIONNAIRE

BACKGROUND INFORMATION:

Please provide the following biographical information by ticking the appropriate block, and by filling in the relevant information where required.

1. AGE

Below 20	20-29	30-39	40-49	50+

2. GENDER

Female	Male

3. HOME LANGUAGE

Afrikaans	English	Xhosa	Zulu	Afrikaans and English	Other(please specify)

4. COHABITATION STATUS

Divorced	Married	Separated	Unmarried and living with other(s)	Unmarried and living alone	Widowed

5. DETAILS OF CHILDREN

No. of children	Pre-school	Primary school	Secondary school	College/ Technikon/ University	Other

6. RELIGION

Agnostic	Atheist	Buddhist	Christian	Hindu	Jewish	Muslim	Undefined	Other(specify)

7. How religious do you consider yourself (Circle the appropriate number)

1	2	3	4	5	6	7
Very religious						Not at all religious

8. IN THE PAST 6 MONTHS HOW OFTEN HAVE YOU ATTENDED CHURCH/MOSQUE/TEMPLE ETC.

Very often (weekly)	Often (monthly)	Not so often (every 6 months or less)	Not at all

9. HIGHEST EDUCATIONAL QUALIFIATION?

Primary School Sub A – Std 5	Secondary School Std 6 –Std 9	Matriculation Std 10	Nursing Diploma/ Degree	Other(specify)

10. What is the name of the area where you live?...

11. How many people live in your house?...

12. How many rooms are in your house?...

13. MONTHY INCOME?

0-R500	R500-R1500	R1500-R2500	R2500-R3500	R3500+

14. What is the total financial contribution from all the people living in your house?...

15. How many years have you been providing home-based care?..........................

16. What work did you do before this?
....
....
....

17. How many people living with HIV/AIDS are you currently providing home-based care for ? ....

WAYS OF COPING QUESTIONNAIRE:

To respond to the statements below, you need to think of the home-based care work that you are doing with people who are living with AIDS. Think of a specific stressful situation that you have experienced in the past week.

By stressful we mean a situation that was difficult or troubling for you, either because you felt distressed about what happened, or because you had to use a considerable effort to deal with the situation. Before responding to the statements, think about the details of this stressful situation, such as where it happened, who was involved, how you acted, and why it was important to you. While you may still be involved in the situation, or it could have already happened, it should be the most stressful situation that you experienced during the week.

As you respond to each of the statements, please keep this stressful situation in mind. Read each statement carefully and indicate, by making an X over the appropriate number, to what extent you used it in the situation.

Use the following scale

0	**1**	**2**	**3**
Does not apply or not used	Used somewhat	Used quite a bit	Used a great deal

Example

Statement: I slept more than usual.............................. 0 1 2 3

If you never slept more than usual, you would mark an X over the number "0" (zero). If you slept (an hour or so more) somewhat more than usual, you would mark an X over the number "1" (one). If you slept quite a bit more (a few hours more, but not daily) you would mark an X over the number "2" (two). If you slept a great deal more (a few hours more daily) you would mark an X over the number "3"(three).

Remember each item refers to how you responded to a stressful encounter during your work with people living with AIDS.

Please indicate mark an X over the appropriate number.

		Does not apply or not used	Used somewhat	Used quite a bit	Used a great deal
1	I just concentrated on what I had to do next–the next step	0	1	2	3
2	I tried to analyze the problem in order to understand it better	0	1	2	3
3	I turned to work or another activity to take my mind off things	0	1	2	3
4	I felt that time would make a difference- the only thing to do was to wait	0	1	2	3
5	I bargained or compromised to get something positive from the situation	0	1	2	3
6	I did something that I didn't think would work, but at least I was doing something	0	1	2	3
7	I tried to get the person responsible to change his or her mind	0	1	2	3
8	I talked to someone to find out more about the situation	0	1	2	3
9	I criticized or lectured myself	0	1	2	3
10	I tried not to burn my bridges, but leave things open somewhat	0	1	2	3
11	I hoped for a miracle	0	1	2	3
12	I went along with fate, sometimes I just have bad luck	0	1	2	3
13	I went on as if nothing had happened	0	1	2	3
14	I tried to keep my feelings to myself	0	1	2	3
15	I looked for a silver lining, so to speak, I tried to look on the bright side of things	0	1	2	3
16	I slept more than usual	0	1	2	3
17	I expressed anger to the person(s) who caused the problem	0	1	2	3
18	I accepted sympathy and understanding from someone	0	1	2	3
19	I told myself things that helped me feel better	0	1	2	3
20	I was inspired to do something creative about the problem	0	1	2	3
21	I tried to forget the whole thing	0	1	2	3
22	I got professional help	0	1	2	3
23	I changed or grew as a person	0	1	2	3
24	I waited to see what would happen before doing anything	0	1	2	3
25	I apologized or did something to make up	0	1	2	3
26	I made a plan of action and followed it	0	1	2	3
27	I accepted the next best thing to what I needed	0	1	2	3
28	I let my feelings out somehow	0	1	2	3
29	I realized I had bought the problem on myself	0	1	2	3
30	I came out of the experience better than when I went in	0	1	2	3
31	I talked to someone who could do something concrete about the problem	0	1	2	3
32	I tried to get away from it for a while by resting, or taking a vacation	0	1	2	3
33	I tried to make myself feel better by eating, drinking, smoking, using drugs or medication etc	0	1	2	3

34	I took a big chance or did something very risky to solve the problem	0	1	2	3
35	I tied to act to hastily or follow my first hunch	0	1	2	3
36	I found new faith	0	1	2	3
37	I maintained my pride and kept a stiff upper lip	0	1	2	3
38	I rediscovered what is important in life	0	1	2	3
39	I changed something so things would turn out alright	0	1	2	3
40	I generally avoided being with people	0	1	2	3
41	I didn't let it get to me, I refused to think too much about it	0	1	2	3
42	I asked for advice from a relative or friend I respected	0	1	2	3
43	I kept others from knowing how bad things were	0	1	2	3
44	I made light of the situation, I refused to get too serious about it	0	1	2	3
45	I talked to someone about how I was feeling	0	1	2	3
46	I stood my ground and fought for what I wanted	0	1	2	3
47	I took it out on other people	0	1	2	3
48	I drew on my past experiences, I was in a similar situation before	0	1	2	3
49	I knew what had to be done, so I doubled my efforts to make things work	0	1	2	3
50	I refused to believe that it had happened	0	1	2	3
51	I promised my self that things would be different next time	0	1	2	3
52	I came up with a couple of different solutions to the problem	0	1	2	3
53	I accepted the situation since nothing could be done	0	1	2	3
54	I tired to keep my feelings about the problem from interfering with other things	0	1	2	3
55	I wished that I could change what had happened or how I felt	0	1	2	3
56	I changed something about myself	0	1	2	3
57	I day dreamed or imagined a better time or place than the one I was in	0	1	2	3
58	I wished that the situation would go away or somehow be over with	0	1	2	3
59	I had fantasies or wishes about how things might turn out	0	1	2	3
60	I prayed	0	1	2	3
61	I prepared myself for the worst	0	1	2	3
62	I went over in my mind what I would say or do	0	1	2	3
63	I thought about how a person I admire would handle this situation and used that as a model	0	1	2	3
64	I tried to see things from the other person's point of view	0	1	2	3
65	I reminded myself how much worse things could be	0	1	2	3
66	I jogged or exercised	0	1	2	3

- Describe in a few sentences what do you consider the most stressful aspect of your work? How do you cope with this?

- What do you think would help you to cope better with the stresses of your work with AIDS patients?

I am aware that your time is valuable, thank you for taking the trouble to participate in this study

1.

University of the Western Cape

Psychology Department

Private Bag X17 Bellville 7535 South Africa Telephone: (021) 959-2283/2453
Fax: (021) 959-3515 Telex: 52 6661

July 2001

Dear Carer,

Providing home-based care for people living with HIV/AIDS has been identified as one of the most critical parts of addressing the current AIDS epidemic in our country. There is very little scientific information available regarding the experiences of home-based carers in South Africa. This study aims to begin to investigate how you as a home – based carer deal with the demanding, challenging and extremely valuable work that you do. It also wants to investigate what you find particularly difficult about this work, how you manage these difficulties, and how you may be assisted or supported in this service, in order to ensure your emotional and psychological well being.

Your assistance, in the form of completing the attached questionnaire as truthfully and correctly as possible, is gratefully appreciated. You are not required to write your name on the questionnaire, so anonymity and confidentiality are assured. Please feel free to contact me if you have any queries.

Thank you most sincerely for the time and effort invested in sharing your experiences and insights in this way.

Researcher: Melissa Melnick
Cell: 0833500943
Home: 021 4627643

Supervisor: Nokothula Shabalala

A Place of Quality, A Place to Grow

WAYS OF COPING QUESTIONNAIRE: AFRIKAANS VERSION

AGTERGROND INFORMASIE:

Verskaf asseblief die volgende biografiese informasie deur om die mees paslike blok te merk en die relevante informasie in te vul waar nodig.

17. OUDERDOM

Jonger as 20	20-29	30-39	40-49	50+

18. GESLAG

Vroulik	Manlik

19. HUISTAAL

Afrikaans	Engels	Xhosa	Zulu	Afrikaans en Engels	Ander (noem asseblief)

20. SAAMWOON STATUS

Geskei	Getroud	Woon apart	Ongetroud en saamwonend met 'n/ ander	Ongetroud en woon alleen	Weduwee

21. BESONDERHEDE VAN KINDERS

Getal kinders	Voorskools	Laerskool	Sekondere skool	Kollege/ Tegnikon/ Universitet	Ander

22. GELOOF

Agnosties	Atheisties	Buddhisme	Christen	Hindu	Joods	Moslem	Ongedefinieer	Ander (noem)

23. Hoe gelowig dink u is u (sirkel relevante nommer)

1	**2**	**3**	**4**	**5**	**6**	**7**
Baie gelowig						**Glad nie gelowig**

24. HOE DIKWELS HET U KERK/MOSKEE/TEMPEL/ENS. IN DIE AFGELOPE 6 MAANDE BYGEWOON

Baie dikwels (weekliks)	**Dikwels (maandliks)**	**Nie baie dikwels (elke 6 maande of minder)**	**Glad nie**

25. HOOGSTE OPVOEDKUNDIGE VLAK?

Onder matriek	**Matriekulasie**	**Verpleeging Diploma**	**Verpleeging Graad**	**Ander (noem)**

10. Wat is die naam van die omgewing waar u woon?
…………………………………………

11. Hoeveel mense woon in u huis?

12. Hoeveel kamers is daar in u huis?

13. MAANDLIKSE INKOMSTE?

0-R500	**R500-R1500**	**R1500-R2500**	**R2500-R3500**	**R3500+**

14. Wat is die totale finansiele bydrae van al die mense wat woon in u huis? ………

15. Vir hoeveel jare verskaf u tuis-gebaseerde sorg?……………………..

16. Watter werk het u voorheen gedoen?
……………………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………

17. Vir hoeveel mense wat leef met HIV/VIGS verskaf u tans tuis-gebaseerde sorg?
……………………………………………………………………

VRAELYS OMTRENT LEWENSHANTERINGSTEGNIEKE

Om kommentaar te lewer op die stellings wat volg, moet u dink aan u tuis-gebaseerde sorgwerk met persone wat met VIGS lewe. Dink aan 'n spesifieke, stresvolle situasie wat u in die afgelope week ervaar het..

'n Stresvolle situasie beteken vir ons 'n situasie wat vir u moeilik of was, spanning veroorsaak het, omdat u bedroef/onsteld gevoel het oor wat gebeur het, of omdat dit baie geverg het om die situasie te hanteer . Dink aan die besonderhede van die situasie voordat u op die stellings reageer lewer, byvoorbeeld waar dit gebeur het, wie was betrokke, hoe u gereageer het, en waarom dit vir u belangrik was. Terwyl u tans nog betrokke kan wees in die situasie, of dit alreeds kon gebeur het, moet dit die mees stresvolle situasie wees wat u hierdie week ervaar het. Hou asseblief hierdie stresvolle situasie in gedagte terwyl u komentaar lewer op elke stelling. Lees elke stelling noukeurig en bevestig tot watter mate u dit in die situasie gebruik het, deur om 'n X oor die paslike nommer te maak.

GEBRUIK DIE VOLGENDE SKAAL

0	**1**	**2**	**3**
Is nie van toepassing, of nie gebruik nie	'n Bietjie gebruik	Nogal baie gebruik	Baie gebruik

VOORBEELD

Stelling: Ek het meer as gewoonlik geslaap………………… 0 1 2 3

As u nooit meer as gewwonlik geslaap het nie, sou u 'n X maak oor die nommer "0" (nul). As u 'n bietjie ('n uur of so) meer as gewoonlik geslaap het, sou u 'n X maak oor die nommer "1". As u nogal baie meer as gewoonlik geslaap het (a paar ure meer, maar nie daagliks nie), sou u 'n X maak oor die nommer "2". As u baie meer geslaap het, (daagliks a paar ure meer), sou u 'n X maak oor die nommer "3".

Onthou, elke item verwys na hoe u gereageer het teenoor 'n stresvolle situasie gedurende u werk met mense wat lewe met HIV/VIGS.

Merk asseblief met ‘n X oor die paslike nommer.

		Is nie van toepassing, of nie gebruik nie	‘n Bietjie gebruik	Nogal baie gebruik	Baie gebruik
1	Ek het net gekonsentreer op wat ek volgende moes doen – die volgende stap	0	1	2	3
2	Ek het die probleem probeer analiseer om dit beter te verstaan	0	1	2	3
3	Ek het begin werk op iets anders om my gedagtes van dinge af te kry	0	1	2	3
4	Ek het gevoel tyd sal ‘n verskil maak – die enigste ding om te doen was om te wag	0	1	2	3
5	Ek het in kompromie aan gegaan on iets positief uit die situasie te kry	0	1	2	3
6	Ek het iets gedoen wat ek nie gedink het sal werk nie, sodat ek ten minste iets daaromtrent doen	0	1	2	3
7	Ek het probeer om die betrokke persoon sy siening te laat verander	0	1	2	3
8	Ek het met iemand gepraat, om meer omtrent die situasie uit te vind	0	1	2	3
9	Ek het myself gekritiseer of vermaan	0	1	2	3
10	Ek het probeer om nie die terugtog onmoontlik te maak nie, maar eerder om dinge ietwat oop te los	0	1	2	3
11	Ek het gehoop vir ‘n wonderwerk	0	1	2	3
12	Ek het die noodlot aanvaar, partykeer het ek slegte geluk	0	1	2	3
13	Ek het gemaak asof niks gebeur het nie	0	1	2	3
14	Ek het probeer om my gevoelens vir myself te hou	0	1	2	3
15	Ek het vir die silwer rantjie gesoek, met ander woorde ek het die ligkant van dinge probeer sien	0	1	2	3
16	Ek het meer as gewoonlik geslaap	0	1	2	3
17	Ek het my woede uitgespreek teen die persoon wat die probleem veroosaak het	0	1	2	3
18	Ek het iemand anders se meegevoel en begrip aanvaar	0	1	2	3
19	Ek het dinge vir myself gese wat my beter laat voel het	0	1	2	3
20	Ek was geinspireer om iets vindingryk omtrent die probleem te doen	0	1	2	3
21	Ek het die hele ding probeer vergeet	0	1	2	3
22	Ek het profesionele hulp gekry	0	1	2	3
23	Ek het verander of gegroei as ‘n persoon	0	1	2	3
24	Ek het gewag om te sien wat sal gebeur, voordat ek enigiets gedoen het	0	1	2	3
25	Ek het om verskoning gevra of iets gedoen om dinge beter te maak	0	1	2	3
26	Ek het ‘n aksieplan gemaak en het dit gevolg	0	1	2	3
27	Ek het die tweede beste ding aanvaar as wat ek benodig het	0	1	2	3
28	Ek het op ‘n manier my gevoelens laat uitkom	0	1	2	3
29	Ek het besef dat ek die probleem op myself gebring het	0	1	2	3

30	Ek was na die ondervinding beter as voor dit	0	1	2	3
31	Ek het met iemand gepraat wat iets prakties /konkreet kon doen omtrent die probleem	0	1	2	3
32	Ek het probeer weg kom vir 'n rukkie, deur om 'n vakansie te neem of 'n bietjie te rus	0	1	2	3
33	Ek het myself probeer beter laat voel deur te eet, drink, rook, of medisyne of dwelms te gebruik	0	1	2	3
34	Ek het 'n groot kans of 'n risiko geneem om die probleem op te los	0	1	2	3
35	Ek het probeer om haastig op te tree, of om my eerste voorgevoel te vertrou	0	1	2	3
36	Ek het nuwe /hernude geloof gevind	0	1	2	3
37	Ek het my trots behou en probeer moed hou	0	1	2	3
38	Ek het dit wat belangrik is in die lewe herontdek	0	1	2	3
39	Ek het iets verander sodat dinge reg sou uitdraai	0	1	2	3
40	Ek het in die algemeen vermy om met mense te wees	0	1	2	3
41	Ek het dit my nie laat affekteer nie, ek het gewyer om te veel daaroor te dink	0	1	2	3
42	Ek het 'n famililied of 'n vriend wie ek respekteer om raad gevra	0	1	2	3
43	Ek het nie laat weet hoe sleg dinge was nie	0	1	2	3
44	Ek het lig gemaak van die situasie, ek het gewyer om te ernstig daaroor te raak	0	1	2	3
45	Ek het met iemand gepraat oor hoe ek gevoel het	0	1	2	3
46	Ek het my man gestaan en geveg vir dit wat ek wou he	0	1	2	3
47	Ek het dit op ander mense uitgehaal	0	1	2	3
48	Ek het van vorige ondervindinge gebruik gemaak, want ek was voorheen in 'n soortgelyke situasie	0	1	2	3
49	Ek het geweet wat gedoen moet word en het daaraom my pogings verdubbel om dinge te laat werk	0	1	2	3
50	Ek het gewyer om te glo wat gebeur het	0	1	2	3
51	Ek het myself belowe dat dinge volgende keer anders sal wees	0	1	2	3
52	Ek het met 'n paar verskillende oplossings tot die probleem opgekom	0	1	2	3
53	Ek het die situasie aanvaar, want niks kon gedoen word nie	0	1	2	3
54	Ek het probeer om my gevolens omtrent die probleem nie met ander dinge te laat inmene nie	0	1	2	3
55	Ek het gewens ek kon verander wat gebeur het of hoe ek gevoel het	0	1	2	3
56	Ek het iets omtrent myself verander	0	1	2	3
57	Ek het in dagdrome of my gedagtes aan 'n beter plek of tyd gedink as die waarin ek toe was	0	1	2	3
58	Ek het gewens die situasie sal weg gaan of op 'n manier oor wees	0	1	2	3
59	Ek het fantasiee of wense gehad oor hoe dinge mag uitdraai	0	1	2	3
60	Ek het gebid	0	1	2	3
61	Ek met myself op die ergste voorberei	0	1	2	3
62	Ek het in my gedagtes oorgegaan wat ek sou se of doen	0	1	2	3
63	Ek het gedink aan hoe 'n persoon wat ek admireer hierdie situasie sou hanteer en het dit as 'n model gebruik	0	1	2	3
64	Ek het probeer om dinge te verstaan van die ander persoon se siening	0	1	2	3

65	Ek het myself herinner aan hoeveel erger dinge kon wees	0	1	2	3
66	Ek het gedraf of liggaamsoeffeninge gedoen	0	1	2	3

- Beskryf in 'n paar sinne wat u dink is die mees stresvolle aspek van u werk. Hoe hanteer u dit ?

- Wat dink u sou u help omdie stres van u werk met VIGS-pasiente beter telaat hanteer?

- Ek is bewus van die feit dat u tyd kosbaar is, daarom wil ek u innig dank vir die moeite wat u gedoen het om deel te neem aan hierdie studie

THE WAYS OF COPING QUESTIONNAIRE: XHOSA VERSION

INKCAZO-MVELAPHI

Nceda sinike ezi nkcukacha zilandelayo zobomi bakho. Kwenze oko ngokufaka uphawu endaweni efanelekileyo nangokubhala iinkcukacha ezifanelekileyo apho zifuneka khona.

1.UBUDALA

Below 20 Ngaphantsi kuka-20	**20-29**	**30-39**	**40-49**	**50+**

2.ISINI

Female/Ibhinqa	**Male/Indoda**

3. ULWIMI LWENKOBE

Afrikaans IsiBhulu	**English IsiNgesi**	**Xhosa IsiXhosa**	**Zulu IsiZulu**	**Afrikaans and English IsiBhulu nesiNgesi**	**Other(please specify) Olunye (luxele)**

4. IMEKO YOKUHLALISANA OKANYE YOMTSHATO

Divorced/ Omtshato uqhawuliweyo	**Married/ Otshatileyo**	**Separated/ - Abahlukeneyo**	**Unmarried and living with other(s)/ Ongatshatanga kodwa ohlala nabanye abantu**	**Unmarried and living alone Ongatshatanga nohlala yedwa**	**Widowed Ongumhlolokazi okanye umhlolo**

5/6. IINKCUKACHA ZABANTWANA

No. of children Inani labantwana	**Pre-school Isikolo sokulondoloza abantwana**	**Primary school/ Isikolo samabanga aphantsi**	**Secondary school/ Isikolo samabanga aphakamileyo**	**College/ Technikon/ University Ikoleji/Ikoloji yezobugcisa/Idyunivesithi**	**Other/ Enye**

7. UKHOLO

Agnostic/ Ongakholwayo kwinto engabonakaliyo	Atheist / Ongakholwayo	Buddhist/ UmBuddist	Christian/ UmKrestu	Hindu/ UmHindu	Jewish/ UmJuda	Muslim/ UmIslam	Undefined / Ongachazwanga	Other(specify) Omnye (xela)

8. Ucinga okokuba ukholwe kangakanani (Yenza isangqa endaweni efanelekileyo)

1	2	3	4	5	6	7
Very religious -Kholwe kakhulu						Not at all religious/ -- Kholwanga konke konke

9. KWISITHUBA SEENYANGA EZISITHANDATHU EZIGQITHILEYO UBUYIHAMBA KANGAKANANI ICAWA, IMOSQUE, ITEMPILE, NJL. NJL.

Very often (weekly) Kaninzi ninzi (njalo ngeveki)	Often (monthly) Kaninzi (njalo ngenyanga)	Not so often (every 6 months or less) Hayi kaninzi (njalo ngeenyanga ezintandathu okanye ngaphantsi)	Not at all/ Nakanye

10.HIGHEST EDUCATIONAL QUALIFICATION?
ESONA SIQINISELO SIPHEZULU SEMFUNDO?

Primary School/ Isikolo samabanga aphantsi Sub A – Std 5	Secondary School/ Isikolo samabanga aphakamileyo Std 6 –Std 9	Matriculation/ Imatriki Std 10	Nursing Diploma/ Degree Idiploma kweZobongi/ Isidanga	Other(specify) Enye (yixele)

11. Yintoni igama lendawo ohlala kuyo?

…………………………………………

12. Bangaphi abantu abahlala endlwini yakho?

…………………………………………………

13.Mangaphi amagumbi endlwini yakho?

…………………………………………………

14.INGENISO NGENYANGA?

0-R500	R500-R1500	R1500-R2500	R2500-R3500	R3500+

15.Ingakanani xa iyonke ingeniso yabantu abahlala endlwini yakho?

16.Mingaphi iminyaka usenza lo msebenzi wokunakelela abantu endlwini yakho?

………………………

17.Wawusenza msebenzi mni ngaphambi kwalo?

……

……

……

18.Bangaphi ngoku abantu abonogawulayo obancedayo ngokubanakelela ekhaya?

…………………………………………………………………………

Iindlela zokuphendula iphepha lemibuzo

Xa uza kuphendula imibuzo ebuziweyo kuza kufuneka ukuba ucinge ngomsebenzi wokongela ekhaya owenzayo ukunceda abantu abanesifo seAIDS. Cinga ngemeko eqhekeza ubuchopho nokhe wadibana nayo kwiveki egqithileyo.

Ngemeko eqhekeza ubuchopho sithetha imeko enzima nekukhathazile kakhulu ngenxa yokuba ibikuza entloko okanye kuye kwafuneka wenze umzama omkhulu ukuhlangabezana nayo. Phambi kokuba uphendule cinga ngazo zonke iinkcukacha zala meko iqhekeza ubuchopho, iinkcukacha ezinjengokuba ibisenzeka phi, ngoobani ababechaphazeleka kuyo, wahlangabezana njani wena nayo, yaye yintoni eyayisenza okokuba ibaluleke kangaka kuwe. Nangona kusenokwenzeka ukuba imeko le usajongene nayo, okanye yimeko eyenzeke yagqitha, kumele ukuba kube yeyona meko ekhe yakuqhekeza ubuchopho apha evekini.

Njengoko uphendula umbuzo ngamnye, nceda yigcine engqondweni into yokuba ujongene nemeko eqhekeza ubuchopho nenxunguphalisa umphefumlo wakho. Funda inqaku ngalinye ngenyameko ubeke uphawu u-X phezu kwenani olikhethileyo ukubonisa izinga lemeko obuzifumana ukuyo.

SEBENZISA LO MLINGANISELO ULANDELAYO

0	**1**	**2**	**3**
Does not apply or not used	Used somewhat	Used quite a bit	Used a great deal
Nakanye	Noko	Kancinci	Kakhulu

UMZEKELO

Statement: I slept more than usual 0 1 2 3

Inqaku: Ndalala ngaphezu kwesiqhelo

Ukuba akuzange ulale ngaphezu kwesiqhelo, faka uphawu u-X phezu kwenombolo u"o'(zero).Ukuba bekukhe kwenzeke ukuba ulale iyure okanye into engaphezu kweyure ukudlula ixesha lesiqhelo, kumele ukuba ufake uphawu u-X phezu kwenombolo"1" (one). Ukuba noko ubugqithisa nje kancinci ngaphezu kwesiqhelo (iiyure ezimbalwa, kodwa hayi zonke iintsuku) faka uphawu u-X phezu kwenombolo u "2" (two). Ukuba ubulala ixesha elide lee kwelesiqhelo (iiyure ezimbalwa ngaphezulu zonke iintsuku), faka uphawu u-X phezu kwenombolo "3" (three).

Khumbula ukuba inqaku ngalinye lisingisele kwindlela obumelana ngayo nemeko eqhekeza ubuchopho nedala ukunxunguphala komphefumlo ngexesha ubusebenza ngabantu abaneAIDS.

Nceda yenza uphawu u-X phezu kwenani elifanelekileyo

		Does not apply or not used Nakanye	Used somewhat Noko	Used quite a bit Kancinci	Used a great deal Kakhulu/Kaninzi
1	I just concentrated on what I had to do next–the next step Ndamilisela ingqondo yam kwinyathelo elilandelayo	0	1	2	3
2	I tried to analyze the problem in order to understand it better Ndazama ukuhlalutya ingxaki ndijonge ukuyiqonda bhetele.	0	1	2	3
3	I turned to work or another activity to take my mind off things Ndazama ukwenza umsebenzi othile ndisenzela ukususa ingqondo yam kule meko.	0	1	2	3
4	I felt that time would make a difference- the only thing to do was to wait Ndazixelela ukuba umahluko uza kubakho ngokuhamba kwexesha, ngako ke ndimele ukulinda.	0	1	2	3
5	I bargained or compromised to get something positive from the situation Ndazama ukuhlangabezana nemeko ngenjongo yokuzizuzela into engandinika ithemba kwimeko leyo endandikuyo	0	1	2	3
6	I did something that I didn't think would work, but at least I was doing something Ndenza into endingazange ndicinge ukuba ingasebenza – kodwa ke ndazama ukwenza into.	0	1	2	3
7	I tried to get the person responsible to change his or her mind Ndazama ukuba lo mntu wayengunobangela wayo yonke le nto ayiguqule ingqondo yakhe	0	1	2	3
8	I talked to someone to find out more about the situation Ndathetha nomnye umntu ndijonge ukufumana ulwazi oluthe chatha ngemeko leyo	0	1	2	3
9	I criticized or lectured myself Ndaba nokuzigxeka kwanokuzifundisa	0	1	2	3
10	I tried not to burn my bridges, but leave things open somewhat Ndazama ukungawavingci amathuba okubuya umva, ndazama ukuwashiya amathuba oko evulekile	0	1	2	3
11	I hoped for a miracle Ndaba nethemba lokwenzeka kwemilingo	0	1	2	3
12	I went along with fate, sometimes I just have bad luck Ndazixelela ukuba okudaliweyo kudaliwe, umntu maxa wambi izinto azimhambeli kakuhle	0	1	2	3
13	I went on as if nothing had happened Ndangcambaza nje ngokungathi akwenzekanga nto	0	1	2	3
14	I tried to keep my feelings to myself Ndazama okokuba uvakalelo lwam ndilugcine kum	0	1	2	3
15	I looked for a silver lining, so to speak, I tried to look on the bright side of things Ndazama ukuzixelela ukuba izinto ziya kulunga ngenye	0	1	2	3

	imini				
16	I slept more than usual Ndalala ngaphezu kwesiqhelo	0	1	2	3
17	I expressed anger to the person(s) who caused the problem Ndabonakalisa umsindo kuloo mntu okanye abo bantu babengunobangela wengxaki	0	1	2	3
18	I accepted sympathy and understanding from someone Ndamkela uvelwano nokuqondwa komnye umntu	0	1	2	3
19	I told myself things that helped me feel better Ndazixelela izinto ezandenza ndaziva ndibhetele	0	1	2	3
20	I was inspired to do something creative about the problem Ndaba nomoya nomdla wokuyila izinto ezintle ngale ngxaki	0	1	2	3
21	I tried to forget the whole thing Ndazama ukuyiphosa kwichibi lokulibala yonke le nto	0	1	2	3
22	I got professional help Ndafumana uncedo ebantwini abaqeqeshelwe ukunceda	0	1	2	3
23	I changed or grew as a person Ndatshintsha okanye ndakhula ndaba mntu wumbi	0	1	2	3
24	I waited to see what would happen before doing anything Ndahlala ndajonga into elandelayo eyayiza kwenzeka phambi kokuba ndiqalise ukwenza nantoni na	0	1	2	3
25	I apologized or did something to make up Ndacela uxolo okanye ndenza ndizama ukubuyekeza	0	1	2	3
26	I made a plan of action and followed it Ndaziyilela inkqubo ndayilandela kakuhle	0	1	2	3
27	I accepted the next best thing to what I needed Ndafa namthanyana ndamkela into enganeno kuleyo ndandiyifuna	0	1	2	3
28	I let my feelings out somehow Ndazama ukuzibonakalisa iimvakalelo zam	0	1	2	3
29	I realized I had bought the problem on myself Ndaqaphela okokuba ndazifaka ngokwam engxakini	0	1	2	3
30	I came out of the experience better than when I went in Ndaphuma kule nto ndibhetele kakhulu kunangaphambili	0	1	2	3
31	I talked to someone who could do something concrete about the problem Ndathetha nomntu owayenokwenza into ephathekayo ngale ngxaki	0	1	2	3
32	I tried to get away from it for a while by resting, or taking a vacation Ndazama ukuphuma okwexeshana kule nto ngokuphumla okanye ukuya ekhefini	0	1	2	3
33	I tried to make myself feel better by eating, drinking, smoking, using drugs or medication etc Ndazama ukuzenza ndizive ndibhetele ngokutya nokusela nokutshaya ndisebenzisa iziyobisi okanye amachiza	0	1	2	3
34	I took a big chance or did something very risky to solve the problem Ndazama ukusombulula le ngxaki ngokwenza into eyingozi kakhulu	0	1	2	3
35	I tied to act too hastily or follow my first hunch Ndagxabhagxabhazisa ndizama ukulandela uvakalelo lwam.	0	1	2	3

36	I found new faith Ndafumana ukholo olutsha	0	1	2	3
37	I maintained my pride and kept a stiff upper lip Ndathiwa lwale likratshi ndangachukumiseki	0	1	2	3
38	I rediscovered what is important in life Ndabhaqa kwakhona eyona nto ibalulekileyo ebomini	0	1	2	3
39	I changed something so things would turn out alright Ndajika nto ithile khon'ukuze izinto zonke zihambe ngokufanelekileyo	0	1	2	3
40	I generally avoided being with people Ndazama ngako konke ukuzikhwebula ebantwini	0	1	2	3
41	I didn't let it get to me, I refused to think too much about it Andizange ndiyivumele ukuba indiphathe kakubi, ndazama ukungacingi ngayo kakhulu	0	1	2	3
42	I asked for advice from a relative or friend I respected Ndacela icebiso kwisihlobo okanye umhlobo wam endimhloniphayo	0	1	2	3
43	I kept others from knowing how bad things were Ndenza ukuba abanye bahlale bengazi ukuba kubi	0	1	2	3
44	I made light of the situation, I refused to get too serious about it Ndayenza ncinci yonke le nto, ndandingafuni ukucinga kakhulu ngayo	0	1	2	3
45	I talked to someone about how I was feeling Ndathetha nomntu ngemeko nendlela endandivakalelwa ngayo	0	1	2	3
46	I stood my ground and fought for what I wanted Ndema ndayilwela into endandiyifuna	0	1	2	3
47	I took it out on other people Ndayikhuphela kwabanye abantu	0	1	2	3
48	I drew on my past experiences, I was in a similar situation before Ndazama nokusebenzisa amava am angaphambili xa ndandikwimeko efana nale	0	1	2	3
49	I knew what had to be done, so I doubled my efforts to make things work Ndandiyazi into emayenziwe, ke ngoko ndenza iinzame eziphindaphindiweyo ukuzuza impumelelo	0	1	2	3
50	I refused to believe that it had happened Ndandingafuni ukuyikholelwa into yokuba le nto yenzekile	0	1	2	3
51	I promised myself that things would be different next time Ndazithembisa ukuba izinto azisayi kufana kwixesha elizayo	0	1	2	3
52	I came up with a couple of different solutions to the problem Ndathi gqi nezisombululo ezingafaniyo zale ngxaki	0	1	2	3
53	I accepted the situation since nothing could be done Ndayamkela imeko njengoko kwakungekho nto inokwenziwa	0	1	2	3
54	I tired to keep my feelings about the problem from interfering with other things Ndazama ukuba indlela endiphatheke yiyo yile nto ingazichaphazeli ezinye izinto	0	1	2	3
55	I wished that I could change what had happened or how I felt Ndandinga ndingayiguqula into eyenzekileyo okanye indlela endandiphatheke ngayo	0	1	2	3

56	I changed something about myself Ndaba nento endiyitshintshayo apha kum esiqwini	0	1	2	3
57	I daydreamed or imagined a better time or place than the one I was in Ndaba namaphupha ndanemibono yam ndikwimeko nasendaweni emnandi engeyiyo le ndandikuyo	0	1	2	3
58	I wished that the situation would go away or somehow be over with Ndaba nomnqweno wokuba imeko leyo yayiza kuphela okanye igqithe	0	1	2	3
59	I had fantasies or wishes about how things might turn out Ndandinamaphupha nemibono malunga nendlela izinto ezaziza kujika zibe yiyo	0	1	2	3
60	I prayed Ndathandaza	0	1	2	3
61	I prepared myself for the worst Ndazilungiselela okubi okwakuza kwehla	0	1	2	3
62	I went over in my mind what I would say or do Ndandisoloko ndijikajikana nayo engqondweni into endandiza kuyenza okanye endandiza kuyithetha	0	1	2	3
63	I thought about how a person I admire would handle this situation and used that as a model Ndacinga ngendlela umntu endimthandayo awayeza kuqhuba ngayo kwimeko elolu hlobo abe ngumzekelo	0	1	2	3
64	I tried to see things from the other person's point of view Ndazama ukubona izinto ngohlobo azibona ngalo omnye umntu	0	1	2	3
65	I reminded myself how much worse things could be Ndazikhumbuza ukuba izinto bezisenokuba mbi kakhulu kunoku	0	1	2	3
66	I jogged or exercised Ndabaleka okanye ndankcunkca okanye ndathamba	0	1	2	3

- Chaza ngezivakalisi ezimbalwa ezona zinto ucinga ukuba zidala uxinezeleko emsebenzini wakho? Umelana njani ale meko?

- Ucinga ukuba yintoni engakunceda umelane bhetele noxinezeleko kumsebenzi wakho wabantu abane-AIDS?

diyazi ukuba ixesha lakho linexabiso, enkosi kakhulu ngokuthatha inxaxheba kweli qweba.

APPENDIX B

CODE BOOK- DATA ANALYSIS

1. Age	1=	<20yrs
	2=	20-29
	3=	30-39
	4=	40-49
	5=	50+
2. Gender	1=	Female
	2=	Male
3. Home Language	1=	Afrikanns
	2=	English
	3=	Xhosa
	4=	Zulu
	5=	Afr + Eng
	6=	Other
4. Cohabitation Status	1=	Divorced
	2=	Married
	3=	Separated
	4=	Unmarried and living with others
	5=	Unmarried living alone
	6=	Widowed
5. No. of children	Enter actual number	
6. Religion	1=	Agnostic
	2=	Atheist
	3=	Buddhist
	4=	Christian
	5=	Hindu
	6=	Jewish
	7=	Muslim
	8=	Undefined
	9=	other
7. Religiosity	Likert scale 1 to 7	Very religious to Not very religious
8. Religious Attendence	1=	Very often
	2=	Often monthly
	3=	Not so often
	4=	Not at all

9. Education	1=	Primary school
	2=	Secondary school
	3=	Matric
	4=	Nursing diploma
	5=	other
10. Area	1=	CBD
	2=	N. Suburbs
	3=	S. Suburbs
	4=	Informal settlement
	5=	Township African
	6=	Township Coloured
11. No. of people in your house	1=	1 person
	2=	2 people
	3=	3-4
	4=	> 4
12. No. of rooms in your house	1=	Shack/bachelor flat
	2=	2 rooms
	3=	3 rooms
	4=	4 rooms
	5=	> 4 rooms
13. Monthly income	1=	0-R500
	2=	>R500- R1500
	3=	>R1500 R2500
	4=	>R2500 – R3500
	5=	>R3500
14. Total financial contribution to household	1=	0-R500
	2=	>R500- R1500
	3=	>R1500 R2500
	4=	>R2500 – R3500
	5=	>R3500
15. Years in the field	1=	Less than 1 year
	2=	1 year
	3=	2-3 years
	4=	4-6 years

	5=	> 6 years
16. Previous work	1=	Blue collar, domestic
	2=	Homecare / childcare
	3=	Nursing
	4=	Unemployed / student / school
	5=	other
17. No. of patients currently in your care	1=	0 –1 person
	2=	2 people
	3=	3-6 people
	4=	7-10 people
	5=	> 10 people
18-83 (1-66 WCQ)	0=	Does not apply
	1=	Used somewhat
	2=	Used quite a bit
84. Name of Organisation	1=	Koinonia
	2=	Caring Network
	3=	Namaqualand Aids Project
	4=	Joy for Life
	5=	Red Cross Society