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CAREGIVER BURDEN AND COPING RESPONSES FOR FEMALES
WHO ARE THE PRIMARY CAREGIVER FOR A FAMILY MEMBER
LIVING WITH HIV/AIDS IN KENYA

by

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A dissertation submitted in partial fulfillment of the requirements
for the degree of Doctor of Philosophy
in the Department of Child, Family and Community Sciences
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at the University of Central Florida
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ABSTRACT

Caring for a family member who is ill can be a draining experience (Cooper et al., 2006; Daire, 2002; Zarit et al, 1980). Providing care for a family member that is living with HIV/AIDS is potentially even more stressful because of social meanings associated with HIV/AIDS infection (Stajduhar, 1998) and the contagious nature of the HIV virus (Powell-Cope & Brown, 1992). Research indicates that most caregivers are female (Bunting, 2001; Songwathana, 2000). In Africa women bear the brunt of the burden of providing care for family members who are living with HIV/AIDS (Mushonga, 2001; Olenja, 1999).

This study examined coping factors and caregiver burden among female caregivers (N=116) of a family member living with HIV/AIDS in Kenya. Coping factors were derived from a principal components factor analysis of the fourteen scales on the Brief Cope (Carver, 1997). Caregiver burden was measured using the Zarit Caregiver Burden Inventory. Multiple regression analysis was used to investigate the relationships between caregiver burden and coping factors. Post-hoc multiple regression analyses further investigated the relationship between caregiver burden and caregiver demographic characteristics. The relationship between caregiver burden and care recipient characteristics was also investigated.

The principle components factor analysis of the Brief Cope yielded five coping factors that were labeled: Social support, Hope, Acceptance, Planning, and Disposition. The regression analysis that was conducted to investigate the relationships between these five coping factors and caregiver burden indicated a significant inverse relationship between Hope and caregiver burden. The post-hoc analyses investigating the relationship

between various caregiver and care recipient characteristics indicated a significant relationship between the caregiver's age and caregiver burden, and education level and caregiver burden. An increase in age correlated with a decrease in caregiver burden. An increase in education level correlated with reduced caregiver burden. Implications of the findings for research and practice are discussed.

For Tabitha Njeri Kimemia
Stay well mami, Cherio
You are loved, still

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CHAPTER 1

INTRODUCTION

The Human Immunodeficiency Virus (HIV) is an incurable virus that is transmitted through the exchange of bodily fluids, most notably blood and semen. The chief modes of transmission are sexual contact, perinatal transmission (infection from mother to child during pregnancy, at birth, or through breastfeeding), and blood transfusion (Kenya Ministry of Health, 2001). When an individual becomes infected with HIV, the virus begins to multiply in the body and within a few weeks, that individual becomes infectious to others with whom they may interact in the ways that serve to transmit the virus. AIDS is the secondary stage of HIV during which the immune system is compromised. The criteria for AIDS diagnosis has been set at a CD4 count (red blood cell) that is lower than 200/cubic mm, or the onset of any illness that is among a specified type of opportunistic infections (CDC, 1992). It can take years for an individual to develop AIDS from the time they contract the HIV virus.

As HIV/AIDS infection rates continued to increase globally (CDC, 2004), statistics indicated that Sub-Saharan Africa was the worst affected region with 28.1% adults and children living with HIV/AIDS. Further, 70% of the people living with HIV/AIDS were in Africa (UNAIDS/WHO, 2001). The UNAIDS (2001) report further noted that by 2001, AIDS had killed about 11.5 million people in sub-Saharan Africa, representing over 80% of total global AIDS related deaths. Akinsola (2001) estimated that practically

everyone in the African continent south of the Sahara had in some way been touched by the scourge of HIV, either by the illness and death of a family member, relative or friend

A review of the literature indicated that substantial research existed on the effects of HIV on the infected individuals. However, as Hanson (2002) observed, not much of the existing research specifically addressed the issues of AIDS caregivers. When an individual was diagnosed with HIV/AIDS, the family members were likely to experience much emotional distress as a result of this diagnosis. Therefore, even though they were not infected themselves, they were impacted by the diagnosis of HIV for a loved one. However, the existing literature paid little attention to this population that was continuing to increase with the escalations in the infection rates.

In addition, the little research that existed had mostly been conducted in the developing world where the social and economic environment differed from that of developing countries (D'Cruz, 2004). Many African countries lacked adequate resources to provide care for those infected with HIV/AIDS and the health care system remained inadequate to deliver even basic care (Freeman, 2004; Karim et al. 2002; Moore & Henry, 2005). The health infrastructure in sub-Saharan African countries experienced additional strain from the demands of the HIV/AIDS epidemic. Hospital bed occupancy for persons with HIV/AIDS related conditions ranged from 40% to 70% in some countries (UNAIDS, 2000). The additional demands on an already struggling health care system necessitated a move towards alternative methods of providing care for persons living with HIV/AIDS leading to a greater push towards community or home-based care (Karim, et. al., 2002; Ramanathan, et al., 2002).

Governments in Africa were pushing for home-based care to ease the burden on the already strained medical facilities in Africa (Ramanathan et. al., 2002; UNAIDS, 2001). However, efforts to equip home-based caregivers with the necessary skills and knowledge did not match the efforts to push home-based care. Consequently, when individuals received a positive HIV diagnosis, they were often sent back into their communities where their families took on caregiving duties without much preparation, training, or support (Hanson, 2002; Olenja, 1999). According to Hanson (2002), informal caregivers needed additional preparation and training for the responsibilities that they assumed when they took on the care of an ailing family member.

Campbell (2004) found that home-based care for Persons Living with HIV/AIDS (PLWHA) was optimal because the infected person remained in a familiar environment. Ramanathan et al. (2002) posited that the provision of care at home reduced hospital and transportation costs for families that were already encumbered with other financial struggles, as well as reduced isolation from friends and family. Also, Glajchen et al. (2005) noted that the home became the primary setting for the delivery of care to persons with advanced illness.

There was little understanding about the kind of psychological interventions that would enhance HIV/AIDS care (Vollmer & Valadez, 1999). According to D’Cruz (2004), a fragmented understanding of caregivers’ experiences, “... hampers the creation of effective policies and programmes, underscoring the need to address the gap” (p.73). In order for caregivers to provide the necessary care, it was imperative that they be provided with adequate support (Olenja, 1999). This would best be accomplished if we gained a better understanding of the impact of the disease on caregivers and therefore

made efforts to provide the kind of support that would ease the impact of HIV on the caregiver (Mushonga, 2001).

Vollmer and Valadez (1999) noted that in Africa, care for sick individuals was usually provided by family members. These authors noted that with the continued increase of the epidemic, there would be an increased need for psychological care and support services for persons living with HIV/AIDS as well as their families. Most of the research in this area focused mainly on the medical aspects of HIV and strategies for fostering behavior change to aid HIV prevention while ignoring the mental health and psychosocial implications of the disease (Freeman, 2004; Vollmer & Valadez, 1999). Thus, there was a need to examine the impact of HIV, not only on those who were infected but, also on the caregivers who were equally affected.

This chapter provides an overview of the current HIV/AIDS crisis and its particular impact on the African continent. The rationale for this study as well as the social significance of the study are discussed. This chapter also includes a brief outline of the research questions that will be investigated, a definition of key terms and limitations that are expected to impact the study.

Social significance of the study

While research demonstrated that providing care for a family member that was ill had psychological and emotional impacts on the caregiver (Daire, 2004; Hanson, 2002), little had been done to investigate the impact of caregiving on female caregivers of family members living with HIV/AIDS in Africa. A few studies had been conducted in the

Central Africa region (Nkowane, 1993), Uganda (Sepulveda et al., 2003), Tanzania (Evans, 2005), and South Africa to examine the experiences of caregivers. However, given the current prevalence of the HIV/AIDS in sub-Saharan Africa, these studies barely scratched the surface in looking at the experiences of caregivers. Hanson (2002) noted that although research identified caregiver burden as a major consequence of caregiving, there was little research to systematically explore the specific variables that significantly contributed to caregiver burden.

Additionally, some research found that home-based care was quickly gaining ground as the new mode of caregiving. Glajchen et al. (2005) noted that the home became the primary setting for the delivery of care to persons with advanced illness. The family members who became caregivers often lacked the skills and training that such a complex role required. Olenja (1999) cited family and community as two strengths that people with chronic or terminal illness relied upon over the years. The author also highlighted some benefits of home-based care (e.g., people who were sick or dying preferred to be at home, they were comforted in their homes by their families and friends, relatives could attend to other chores and take care of the patient as well, and homecare was less expensive than hospitalization).

In order to sustain good quality care for HIV/AIDS patients, the morale of caregivers must be sustained through the provision of support of various kinds that would meet the demands of caregiving (Mushonga, 2001; UNAIDS, 2000). Hendrick (2000) underscored the importance of caregivers for persons living with HIV/AIDS because of the role that they played in helping the patient remain at home longer. In the case of caregivers in Kenya however, the abject poverty and inadequate information were key

sources of stress for caregivers (Nyambedha, et al., 2003). These and other challenges that caregivers were faced with must be addressed in order to optimize the benefits of home-based care for both patients and their caregivers.

In discussing caregivers for persons with dementia, Daire (2001) noted that caregivers were often required to provide emotional support as well as provide assistance with the activities of daily living. For individuals caring for a person with HIV/AIDS, the situation was complicated further by the stigma associated with HIV/AIDS (Brown & Powell-Cope, 1992; Bunting, 2001; Olenja, 1999) and the social isolation or rejection that the caregivers experienced as a result of this stigma (Callery, 2000; Olenja, 1999). Caregivers for persons with HIV/AIDS did not typically enjoy the social support that caregivers for persons with other chronic illnesses did. Poindexter & Linsk (1999) found that because of the stigmatizing nature of HIV illness, caregivers were often reluctant to disclose the HIV-diagnosis and therefore, did not seek any help and support.

Olenja (1999) posited that persons who were HIV positive in Kenya enjoyed little sympathy or support from not only the community, but also from health workers. This was largely because their condition was viewed as self-imposed. As a result, the caregivers bore the burden of providing care on their own, sometimes even becoming targets of social stigmatization as well. The tasks involved in the care of the sick person further burdened the caregiver who might already have been dealing with other issues such as financial constraints, the emotional toll of watching a loved one deteriorate in the face of AIDS, and fear of infection.

There was need to take into account the well being of the caregiver, as this in turn impacted the health status of the person receiving care. Cummings et al., (2002)

described the caregiver's well being as critical to the optimal care of the patient. By assessing caregiver burden, counselors and other mental health professionals could implement measures that minimized caregiver stress and thus defer institutionalization of the patient. Zarit (2004) also urged that family caregivers should be recognized as an essential part of the treatment team. This recognition was important in encouraging caregivers to become more confident about their abilities to care for a loved one. Zarit (2004) emphasized the need to assess burden of care, stress levels, and mental health of caregivers and urged that appropriate steps must be taken to prevent caregivers from becoming overwhelmed.

This study will examine the underlying factors among coping responses in female caregivers for a family member that is living with HIV/AIDS in Kenya. The study will also investigate the relationships that exist among coping response factors and caregiver burden in female caregivers for a family member that is living with HIV/AIDS in Kenya. This study aims to demonstrate the need to broaden mental health interventions beyond the current scope of providing counseling to persons living with HIV/AIDS and to formulate systemic interventions that focus on the system of the individual with HIV/AIDS (Bor, Miller & Goldman, 1993). Prevailing counseling approaches were geared towards the individual that was infected and had the purpose of containing infection rates rather than improving their mental well being (Vollmer & Valladez, 2000). The present study will focus on a population that is neglected in the research and interventions in Kenya, that is, the caregiver. Information obtained from the study on coping factors that reduce or increase caregiver burden will also be important in program design and implementation for caregivers, as well as interventions.

Statement of the problem

Kenya is one of the countries that are hardest hit by the HIV/AIDS epidemic. However, current research on the impact of HIV/AIDS in Kenya has been inclined towards looking at the economic impact of the disease on those that are infected without giving due consideration to those that are affected as a result of having to informally provide care for infected family members. A report compiled by the Kenya Ministry of Health (2001) discussed the immense impact that HIV/AIDS had on Kenya across many levels. This report urged the provision of quality care for those who were infected with HIV/AIDS. The report also listed the merits of home-based care for individuals infected with HIV/AIDS. Among the benefits discussed were the easing of the burden of care on the medical sector, involvement of family and community, and a holistic approach to medical care that included counseling, nursing care, nutrition, and social support. However, this report only paid scant attention to family caregivers and the intense strain that caregiving placed on them. Any discussion of caregivers was focused on those who took on the care of AIDS orphans but not on those that provided care to infected individuals.

Prevailing approaches focused on the infected, while largely ignoring those that were directly and indirectly affected through the provision of care for their family members who were infected with the disease. As Kenya continued to grapple with the HIV/AIDS epidemic (Olenja, 1999), families were continually called upon to assume the role of caring for family members living with HIV/AIDS, a task that often fell upon the women in the family. The HIV/AIDS epidemic that gripped the African continent placed many people in the role of caregiver for a family member who was infected with the

disease but the impact of the caregiving had yet to be studied in the unique context of Africa.

Although research found that caregivers were impacted emotionally, financially, socially, and mentally by their duties as caregivers (Daire, 2001; Stajduhar, 1998; Tolliver, 2001; Zarit et al., 1980) the health care system had done little to address caregiver needs (Glajchen et al., 2005). The wellbeing of caregivers was crucial to the patient's wellbeing. In discussing caregivers of persons with Alzheimer's disease, Cummings et al. (2002) observed that the physical and emotional health of the caregiver was critical to the optimal care of the patient.

A search of the literature revealed that research on caregivers of persons living with HIV/AIDS has been done in western countries where most of the infected population had access to medical facilities that were not available in Kenya (Campbell, 2004). While research demonstrated that providing care for a family member that was ill had psychological and emotional impacts on the caregiver (Daire, 2004; Davis, 1998; Gordon & Perrone, 2004; Spurlock, 2002), only a few studies investigated the impact of caregiving on female caregivers of family members living with HIV/AIDS in Africa (Brouwer et al., 2000; Campbell, 2004; Lindsey et al., 2003; Mushonga, 2001; Olenja, 1999). The experiences of caregivers must be examined within their cultural, social, and economic context. The difficulties in accessing health care in Africa, and in particular in Kenya created challenges for caregivers that were unique to them. This rendered most of the research findings on caregivers inapplicable to a Kenyan situation and called for an examination of the phenomena of caregiving as it impacted people specifically in Kenya.

In light of all these factors, it is important to gain an understanding of how female caregivers for family member that is living with HIV/AIDS in Kenya cope with the added demands of caregiving. What coping responses do they utilize in their efforts to ease the caregiver burden? While there is no single experience for the female Kenyan caregiver owing to the multifaceted nature of Kenyan society, an understanding of how female caregivers in Kenya function on a general level will be crucial in providing more specific guidelines for health service providers.

Rationale

According to Hanson (2002), caregivers represented a population of individuals who were in need of support and psychosocial intervention. Caring for a person with a terminal illness had the potential to be a draining experience (Daire, 2001; Zarit et al, 1980). This experience was even more challenging when the care recipient was a family member living with HIV/AIDS (Powell-Cope & Brown, 1992). While research abounded that looked at the experiences of caregivers of persons with debilitating illness such as strokes (Wyller et al., 2001) and Alzheimer's dementia (Cummings et al., 2005; Daire, 2004; Nunley, 2002; Pratt et al., 1985; Spurlock, 2002) the experiences of caregivers for persons with HIV/AIDS were inherently unique because HIV/AIDS bore a social stigma that none of the other illnesses did (Callery, 2000; Kalichman & Simbayi, 2004; Powell-Cope & Brown, 1992). The already strenuous demands of caregiving were further compounded by the social stigma that continued to be associated with HIV/AIDS (Bunting, 2001; D'Cruz, 2004).

Bunting (2001) further noted that in many places around the world, care for individuals who were infected with HIV/AIDS had been relegated to the women in their lives including wives, mothers, daughters and other female family members. The US Department of Health and Human Services (1997) reported that in the United States, women provided over 80% of all informal caregiving in addition to taking care of their other responsibilities. There is plenty of documentation in the literature of women as primary caregivers (McNeil, 1996; Mushonga, 2001; D’Cruz, 2004).

As Kenya continued to grapple with the HIV/AIDS epidemic that gripped the country, it was natural that caring for family members who were ill was a task that was often taken on by the women in the family. The literature reported that men did not normally take on the role of informal caregivers except in situations where there were no women available to do so (Abel, 1991; Hooyman & Gonyea, 1995; Kaye & Applegate, 1990). As a result, the burden of caregiving was traditionally borne by women. This was considered the natural order of things and had not been researched much even when the modalities of care had clearly changed with HIV/AIDS. It was easy to overlook the impact on the caregiver because caring had traditionally been the domain of women (Songwathana, 2001). This might explain why existing research paid so little attention to female caregivers in Africa.

Joseph & Bhatti (2004) found that in many instances, female caregivers for persons living with HIV/AIDS were themselves already infected with the HIV virus especially when the care recipient was a spouse. Songwathana (2001) conducted a study with female caregivers in Thailand and found that nine of the 15 women were HIV positive. Even then, the expectation was that they would take care of their spouses and

their children, with the result that their own health needs suffered. This was highly likely to be the case in African countries too where women were disproportionately affected by HIV, with 13 women living with HIV for every 10 infected men (UNAIDS/WHO, 2004).

Even though some experiences of caregivers were universal, the cultural, economic, and social context in which Kenyan female caregivers performed their duties of caregiving were unique to them. Consequently, the findings of previous studies conducted in the developed world might not apply in a Kenyan context. It is therefore important to study the specific experiences of Kenyan female caregivers as 'human issues and problems are experienced, understood and interpreted in their social and cultural context' (Keeling, 1993). Navaie-Walliser et al. (2001) cited the need for studies that examined specific groups in order to gain a better understanding of the challenges that faced those groups.

The coping responses that people used were also a function of a combination of factors such as economics, culture, and personality. Although coping responses were well researched in western countries (Carver et al., 1989; Folkman, 1997; Rose & Clark-Alexander, 1999), the responses that research identified as most effective were only effective in the context within which they had been studied. Also, Africans utilized coping responses that were specific adaptations to their cultural, economic, social and physical environment (Evans, 2005). As mental health and medical interventions are implemented, it is important to understand how caregiving impacts the caregivers, the majority of whom are female, in order to tailor the interventions to best serve the needs of the targeted clients. The needs of caregivers must be understood so that these caregivers

can be helped to provide care in a compassionate manner for their loved one (Hanson, 2002).

Identification of coping responses and their relationship to caregiver burden among female caregivers for a family member that is living with HIV/AIDS in Kenya will contribute to the body of knowledge in this area. This information will also be useful in the design of mental health interventions that caregivers will find to be helpful. Because counseling is a young profession in Kenya and most of Africa, it is imperative that the profession sets out to conduct needs assessments that will serve as a guide to planned interventions. This study is an example of the needs assessment among caregivers, the result of which will provide useful information for the counseling profession in Kenya.

Purpose of study

The aim of this study will be twofold: to contribute to the understanding of caregiver burden and coping responses among women in Kenya who are providing care for a family member that is living with HIV/AIDS, and to investigate the relationship between caregiver burden and coping responses. The study aims to investigate coping responses among female caregivers for a family member living with HIV/AIDS in Kenya and derive a model of coping response factors that are significant for this population. The study will aim to answer an important question: what are the main coping factors that female caregivers for a family member that is living with HIV/AIDS in Kenya utilize? In doing this, it is hoped that the study will significantly inform practice as well as guide the design of interventions that are used with this population and other female caregivers in

this region of the world. According to Glajchen et al. (2005), the timely identification of caregivers who were experiencing distress was an important factor in the development of clinical programs that provided support or treatment. By measuring caregiver burden, this study will help to identify such caregivers who would benefit from clinical interventions. Additionally, gaining an understanding of coping responses that are found to be effective will help to formulate mental health interventions that will promote emotional and psychosocial well being of the caregivers.

In addition, this study will investigate caregiver burden among female caregivers for a family member living with HIV/AIDS in Kenya and examine how caregiver burden is related to the identified coping factors. It is anticipated that this study will help to answer some significant questions by looking at a population that has been thus far neglected in the provision of services as well as helping to shape the growing profession of counseling. The lack of research that focuses on the experiences of this population underscores the need for more information to guide policy as well as program implementation in the efforts to cater to this population.

Research Questions

This study will seek to examine the following research questions and hypotheses:

- Research Question A: What are the underlying factors among coping responses in female caregivers for a family member that is living with HIV/AIDS in Kenya?
 - *Hypothesis 1* – A factor analysis of the Brief Cope (Carver, 1997) will produce five significant coping factors among female caregivers for a family member that is living with HIV/AIDS in Kenya. Research with the

Brief Cope to investigate post traumatic stress disorder with a population of HIV/AIDS patients in South Africa yielded five significant coping factors for the population that was studied (Olley, Zeier, Seedat, & Stein, 2005). This study will seek to extract five coping factors from the current population in keeping with a priori criterion in factor analysis (Hair et al., 1998).

Research Question B: What relationships exist between coping response factors and caregiver burden in female caregivers for a family member that is living with HIV/AIDS in Kenya?

- *Hypothesis 1* – Coping factors derived from the factor analysis of the Brief Cope will be significant predictors of caregiver burden among female caregivers for a family member that is living with HIV/AIDS in Kenya.

Definition of terms

HIV- Human Immunodeficiency Virus. An incurable virus that is transmitted through the exchange of contaminated bodily fluids, e.g. blood, semen, and breast milk.

AIDS - Acquired Immune Deficiency Syndrome. The secondary stage of HIV infection that is characterized by a CD4 count (red blood cell) that is lower than 200/cubic mm, or the onset of any illness that is among a specified type of opportunistic infections (CDC, 1992). Without access to anti retroviral drugs, an individual with AIDS can expect to live for a period ranging between 6 months to two years.

PLWHA- Person Living with HIV/AIDS: An individual who has received a positive diagnosis of HIV/AIDS. Because of limited access to medical facilities,

individuals with HIV in Kenya may not know their T-cell count. For purposes of this study, PLWHA will refer to any individual that has been diagnosed with HIV regardless of the stage of illness as measured by a T-cell count.

Caregiver: Refers to an individual who assists in the provision of care for a person that is infected with a debilitating illness. This study will focus on female caregivers who are the primary caregiver for a family member that is infected with HIV/AIDS. The study will specifically investigate informal caregivers who are not medical or social work professionals and do not receive any financial remuneration for their work as caregivers.

Caregiver burden: The literature defines caregiver burden as the physical, psychological or emotional, social, and financial problems that family members experience as a result of caring for a relative who has a disability or impairment (George & Gwyther, 1986; Hanson, 2000). For this study, the construct of caregiver burden will be measured by means of the Caregiver Burden Inventory (Zarit, et al, 1990). It will encompass both what is referred to in the literature as objective and subjective burden. These distinctions are discussed in the literature review.

Coping: Refers to the actions that people take to avoid or to reduce the strain of life's problems (Lazarus & Folkman, 1984). The literature uses the terms strategies, responses, behaviors and factors interchangeably to refer to the ways in which the individuals respond to the demands imposed by caregiving. The responses that participants utilize will be measured by use of the Brief Cope (Carver, 1997). Coolidge et al. (2000) grouped the subscales on the Brief Cope into three groups, emotion focused strategies, problem focused strategies, and dysfunctional strategies.

Demographic variables: Research has indicated that personal characteristics such as age, education level, relationship to the care recipient and income level are directly related to the experience of burden (Folkman et al., 1994; Onishi et al., 2005, Pakenham, Dadds & Terry, 1995; Zarit et al., 1980). For this study, the demographic variables will include age of caregiver, relationship to the care recipient, number of years in school, monthly household income, number of persons living in household, age, and HIV status of caregiver.

Kenya Shillings: During the time of the study, the exchange rate of the shilling to the US dollar was \$1=77 Kenya Shillings. The stipend that was given to participants was 150 Kenya shillings, the equivalent of \$2. The daily wage for casual workers in the areas where the respondents were drawn from would range from Kenya Shillings 70-120.

Limitations

Instrumentation: The instruments used in this study have not been normed for use with African populations. The Brief Cope was normed against a predominantly white sample of hurricane survivors in the United States (Carver et al., 1997) while the Zarit Caregiver Burden Interview used a sample of predominantly white caregivers for a person with dementia in the United States (Zarit et al, 1990). As a result, the construct validity of the instruments with the target population in this study is questionable. A review of the literature found no instruments to measure the constructs of interest for this study that had been normed for use with African populations.

Translation: While taking great care to retain the meaning of each translated item, it is likely that in the process of translating the instruments, some of the nuances of the

items may be lost in translation and may not accurately reflect what items are intended to measure. The translation process entails more than linguistic translation but rather, calls for the transferability of concepts across cultures. These concepts may or may not exist in the second language, in this case, Swahili and Kikuyu.

Self-reported measures of burden: As is the case in most cultures, women are socialized to be nurturers and carers. As a result, the task of caring for a family member that is ill may not be seen as anything outside the normal scope of one's duties. Research has found that men report greater levels of caregiver burden, perhaps because caregiving is not naturally a man's task (D'Cruz, 2004; Walker, 2002). In this study, the female caregivers may not report burden as would be expected because of their perception of their role. Additionally, the connotation of burden is negative. To acknowledge burden in caring for a family member who is ill may be seen as complaining and might be socially unacceptable especially when the care recipient is a spouse or a child. As a result, respondents may minimize their experiences or fail to report any perceived burden, thereby skewing the findings of the study.

- Participants accessed through AIDS agencies may already have some support by virtue of their association with these organizations. The use of AIDS agencies to recruit caregivers for the study precludes a bias.

CHAPTER 2

LITERATURE REVIEW

This chapter will present previous research literature that is relevant to the study of female caregivers for a family member that is living with HIV/AIDS. The chapter will focus on the status of HIV/AIDS in Africa with a section that addresses the HIV/AIDS epidemic in Kenya. This chapter will also include a review of literature on caregiver burden, with particular attention to caregivers for persons living with HIV/AIDS. The majority of caregivers for PLWHA in Kenya are women. The chapter will examine the existing literature on female caregivers. Finally, coping responses will be discussed.

HIV/AIDS: The African situation

The United Nations termed AIDS as an extraordinary crisis in both the short term and the long term (UNAIDS 2004). The most current report from the UNAID (2005) estimated that there were more than 40 million people living with HIV/AIDS around the globe in the year 2005. Of these, 17.5 million were women and 2.3 million were children. This report also estimated the number of AIDS deaths in 2005 to have exceeded 3 million. Efforts to contain the epidemic had only been minimally successful, with the infection rates rising faster than the response. It was estimated that in the year 2003, there were over 3 million new infections in sub-Saharan Africa, with the epidemic spreading steadily across Europe and Asia. The UNAIDS Report (2004) further noted that women made up more than half of all persons living with HIV/AIDS in Africa as well as globally. Revised estimates put the numbers of people living with HIV/AIDS at 38

million, in 2003, up from 35 million in 2001 (UNAIDS, 2004). Of these, the overwhelming majority were in the poorest countries.

The worst affected region was sub-Saharan Africa (Patterson, 2005), home to more than 70% of the people living with HIV/AIDS globally (Dixon, McDonald & Roberts, 2002). Onen (2002) reported that no part of the world has experienced the HIV/AIDS crisis on a scale as large as sub-Sahara Africa. UNAIDS (2005) estimated that more than 25 million people were living with HIV/AIDS in sub-Saharan Africa in the year 2005, and that there were over 2.4 million deaths due to AIDS in the same region in the year 2005. The HIV/AIDS epidemic was estimated to have impacted all facets of life in African countries, with decreases in life expectancy, reduction of military forces, and loss of productive labor in society (Patterson, 2005). WHO (1999) reported that at the beginning of the 21st century, AIDS was the leading cause of death in Africa and the fourth leading cause of death in the world.

According to the UNAIDS (2005) report, 25.8 million persons were living with AIDS in sub-Saharan Africa in 2005 and 13.5 million of these were women. There was little evidence of a decline in the HIV epidemic with the exception of Uganda, Kenya and Zimbabwe where there appeared to be a decline in prevalence levels. Southern Africa remained the epicenter of the AIDS crisis, with infection rates at an all time high (UNAIDS, 2005). Prevalence levels exceeding 30% had been recorded in some countries such as Namibia, Lesotho and Swaziland. With the exception of Zimbabwe, there was no evidence of a decline in the other Southern African countries. HIV prevalence remained very high in South Africa, Malawi, Mozambique and Zambia. The East African region

saw some gradual declines in prevalence levels. Indeed, urban Kenya was reported to have had the most dramatic prevalence drop among pregnant women.

As a result of the rising prevalence levels, sub-Saharan Africa faced the greatest demographic toll, with the situation continuing to worsen in most countries. The AIDS epidemic in Africa was made worse by the state of health care in sub-Saharan African countries and the limited access to medical care (Amoroso, Davis, & Redfield, 2002). Mushonga (2001) reported that in Zimbabwe for instance, HIV/AIDS had placed such a burden on the health system that patients were routinely discharged early to be cared for by relatives. The HIV/AIDS epidemic in Africa affected every facet of life. All sectors of government had felt the effects of HIV/AIDS in one way or another (UNAIDS 2004). The agricultural sector, education, health, and labor had all been touched by the scourge of HIV/AIDS. With AIDS related deaths on the rise, workforces ranging from teachers, health and medical personnel, agricultural workers, and miners suffered major setbacks as more and more workers succumbed to the virus.

Most households in Africa had felt the effects of HIV/AIDS either directly or indirectly (Akinsola, 2001). When the individual that was infected with HIV/AIDS was a breadwinner, the family had to find ways to adjust economically. Those that took on the caregiving role often found themselves having to give up some work commitments as a result of the demands of caregiving. A recent study in Tanzania found that the HIV/AIDS epidemic aggravated already existing issues such as chronic poverty, gender inequalities, and social marginalization (Evans, 2005). This study also found that the burden of care for persons living with HIV/AIDS continued to be borne by different generations of women who struggled to provide care in the face of tremendous financial difficulties.

Similar studies conducted among caregivers for HIV/AIDS patients in Zimbabwe (Mushonga, 2001), Togo (Moore & Henry, 2005), Malawi (Lindgren et al., 2005; Uganda (Brouwer et al., 2000) and Kenya (Nyambedha et al., 2003; Olenja, 1999) found that the brunt of the caregiving burden was borne by women.

As the HIV/AIDS epidemics continued to ravage the continent of Africa, the need for solutions that effectively mitigated the burden of care among those that took on that important role of caregiving became even more important. This was particularly important because the traditional strengths of the African extended family that were traditionally expected to serve as a social buffer were no longer in place (Moore & Henry, 2005; Olenja, 1999). Moore & Henry (2005) noted that with the HIV/AIDS epidemic in Africa, social support might be hard to come by even though more caregiving responsibilities were continually heaped upon the family. In this emerging context of restructured families, economic hardship, and HIV stigma, it was important to obtain an understanding of how families coped with the demands of caregiving in the new context of HIV/AIDS

HIV/AIDS in Kenya

In Kenya, the prevalence of HIV/AIDS was as high as in most sub-Saharan African countries (UNAIDS, 2005). Although the United Nations AIDS organization surveillance data identified Kenya as one of three countries in sub-Saharan Africa to have a noted decrease in prevalence rates (UNAIDS, 2005), the statistics were still notably high. Preliminary results from the latest survey by the Kenya Demographic and Health Survey showed that 6.7% of Kenyans were HIV positive (Central Bureau of Statistics

Report, 2004). A report on AIDS in Kenya from the Kenya Ministry of Health estimated that there were about 2.2 million Kenyans living with HIV.

The first case of AIDS was diagnosed in Kenya in 1984 (Rau, Forsythe, & Okeyo, 1996). Since that time, infection rates continued to rise at alarming rates, prompting the Kenya government to declare AIDS as a national crisis in 1993. The onset of AIDS was greeted with cynicism and detachment because at the time, HIV/AIDS was associated with 'gay westerners'. The lack of a prominent gay culture in Kenya led to a sense of security and Kenyans thought they were at little or no risk to contract the virus. Rau et al. (1996) discussed the advent of HIV and the sensationalism surrounding the disease in those early years. Religious leaders in Kenya called for a rejection of what they termed as western solutions such as the use of condoms to stem the spread of HIV. However, as the numbers of new infections continued to rise, the seriousness of the crisis began to become clear and there was a call to action from different parties such as nongovernmental and religious organizations.

The majority of HIV infections in Kenya were transmitted through heterosexual contact (Kenya Ministry of Health, 2001). Other modes of transmission were perinatal transmission, and blood transfusion. The 2001 AIDS report from the Ministry of Health estimated that 30-40% of babies born to infected mothers would be infected too. Blood transfusion was not a common transmission mode because almost 100% of blood was screened prior to transfusion. According to the Ministry of Health (2001), more than 75% of AIDS cases in Kenya occurred in adults aged between 20 and 45. Life expectancy in Kenya was also estimated to be only 46, a steep decrease from the earlier projected age of 65 without AIDS.

The Ministry of health estimated that about 75% of AIDS cases in Kenya occurred among adults aged between 20 and 45. This was the most economically productive part of the population and as a result, the deaths of these individuals caused a huge drain on the economy of the country. Regardless of who was infected in a family, the socioeconomic impact of HIV/AIDS was felt by everyone (Kusimba, et al., 1996). When AIDS related illnesses arose within a family, household members were forced to take time off work to nurse the patient. This impacted the family's financial resources as available funds were spent on health care and other illness related expenses.

Although a positive HIV diagnosis had serious mental health implications, counseling efforts continued to be geared primarily towards reducing transmission. HIV counseling focused on behavior change in order to curb the spread of HIV. The emotional effects of receiving a HIV diagnosis were often not addressed. Voluntary Counseling and Testing centers (VCTs) geared their services to the individual that came in to test for HIV/AIDS, and not much attention was directed to the system into which they returned with their positive diagnosis (Vollmer & Valadez, 1999). The counseling component of the counseling and testing interventions was minimized and greater emphasis was given to the need for a HIV test and provision of test results. The long-term psychological needs of persons with HIV/AIDS and their system were often overshadowed by physical and social needs in a setting with limited resources (Kaaya & Smith-Fawzi, 1999). Prevailing interventions focused on the infected while largely ignoring those that were directly and indirectly affected through the provision of care for sick family members. A search of the literature turned up only three articles related to caregiving for HIV/AIDS persons in Kenya (Ngugi & Njenga, 1995; Nyambedha et al., 2003; Olenja, 1999).

Due to the added strain on the health system, hospital capacity in most African countries was limited and many patients were discharged early to the care of family members (Freeman, 2004; Mushonga, 2001). However, the family members were often unprepared for the role that awaited them, and worse still, had little or no understanding of the disease and its progression (Hendrick, 2000). Most counseling interventions were also largely geared towards the individual, with little regard for their system within which they operated. The family of the individual that was infected was often times not included in any interventions.

In the developed world, people with HIV were living longer because of accessibility of medications that mediated the effects of HIV (Prachakul & Grant, 2003). This was not the case for many people with HIV in Kenya, and in fact, in most of Africa. Most people were economically disadvantaged and could not afford the cocktail of drugs necessary to sustain them. Vollmer & Valadez (1999) noted that care for PLWHA had already overwhelmed the health services in many countries in Africa and that access to ARVs and other HIV/AIDS drugs was limited because of the costs involved.

Existing research on the impact of HIV/AIDS in Kenya focused mostly on the economic impact of the disease on the country. A report compiled by the Kenya Ministry of Health (2001) cited the impact of HIV/AIDS on corporate organizations, commercial agriculture, and smallholder farms. This report further suggested strategies for intervention at various levels, citing the need for improved collaboration between health care providers, communities, and families through better training and mobilization of resources. However, in discussing caregivers, the report only mentioned caregivers who

took on the care of children who were orphaned by AIDS but not family caregivers who provide home-based care for loved ones who were infected.

HIV/AIDS bore a social stigma not shared by other illnesses (Bunting, 2001; Freeman, 2004; Kalichman & Simbayi, 2004; Nzioka, 2000). In a study of caregivers conducted in Zimbabwe, Mushonga (2001) noted that caregivers of persons with HIV/AIDS might not involve other family members as caregivers in other situations did for fear of stigmatization and isolation. In Kenya, the prevailing denial by those infected and their families posed a challenge both for control of the infection rates and caring for the infected (Nzioka, 2000; Olenja, 1999).

As governments in African pushed towards home-based care for infected persons, the sheer numbers of those infected were overwhelming to an already overburdened community (Olenja, 1999). This author also noted that the family structure in Kenya had undergone such tremendous transformations over the years such that the extended family and community that would have traditionally been a source of support was no longer available in most cases. Rural-urban migration and other economic realities had transformed the manner in which society operated and the structures of social support that would have been instrumental in times of need were no longer in place. Olenja further found that poverty, inadequate space and insufficient information about HIV/AIDS further complicated the duties of caring for a person living with AIDS in Kenya. Additionally, because PLWHA were viewed as sexually promiscuous, the community extended little sympathy towards them and this spelt isolation for the entire family.

Nzioka (2000) noted that the individual in Kenya did not exist autonomously, but rather as a unit in a collective whole. What happened to an individual had an impact on their family, clan and community. In a discussion of the impact of HIV/IDS within the family in Kenya, Kusimba et al. (1996) stated the following:

Families are likely to be particularly affected by this disease, and their needs must be identified and addressed. Because of the stigma attached to AIDS, some HIV-infected individuals and their families have sought to conceal and/or deny their illness. Denial, anger, blame, guilt and shame are common responses of both individuals and families to HIV. In some cases, family members suffer severe psychological trauma, while in others, the infected engage in self-destructive behaviour.

An extensive study on the role of the elderly as caretakers of AIDS orphans that was conducted in Western Kenya found that the HIV/AIDS epidemic created a reversal of roles, with elderly people taking on the care of their children and their grandchildren. Of 724 children in this study, 243 were orphans as a result of the death of a parent or both parents from AIDS related illnesses. This study identified a new generation of caregivers, persons who were in their twilight years but who now had to take on responsibilities of child rearing in their old age. This study was of interest because some of these caregivers were left with orphans who were infected with HIV. This new role of the elderly as caregivers, often with limited knowledge and access to resources brought new challenges to these individuals, most of whom were women. The findings of this study were also

parallel to studies in other African countries (Brouwer et al., 2000; Moore & Henry, 2005; Mushonga, 2001).

As Kenyan society continued to evolve (Nzioka, 2000; Olenja, 1999), traditional structures that provided social support were no longer readily available. It was important to examine the experiences of caregivers in the emerging context of HIV/AIDS and the unique challenges that came with these experiences. An overview of the concept of caregiver burden as experienced by caregivers of persons with various illnesses will be presented, followed by a review of existing literature on the experiences of caregivers of persons with HIV/AIDS.

Caregiver Burden

Caregiver burden refers to the physical, psychological or emotional, social, and financial problems that family members experience as a result of caring for a relative who has a disability or impairment (George & Gwyther, 1986). Zarit et al. (1980) defined caregiver burden as the extent to which caregivers perceived their emotional or physical health, social life and financial status as being compromised as a result of caring for their relatives. Hanson (2000) referred to caregiver burden as ‘the distress or disruption resulting from caring for someone who is ill’, and discussed two types of burden, objective and subjective burden. Objective burden refers to the disruptions that are observable such as financial strain, relationships, and employment. Subjective burden refers to the distress that involves the caregiver’s feelings, attitudes and emotions (Hanson, 2000).

The construct of caregiver burden received a great deal of attention in the literature. Many studies demonstrated the impact of the caregiving role on the caregiver (Cooper et al., 2006; Zarit et al., 1980). While there was evidence that some caregivers derived immense gratification and personal satisfaction as a result of their involvement in caregiving (Kinney & Stephens, 1989; Motenko, 1989), the majority of caregivers experienced negative consequences of caregiving. Zarit et al., (1998) found stress to be a common consequence of caregiving. Other studies documented the added stress that caregivers experienced as a result of their caregiving roles (Mui, 1992; Rosenvinge et al., 1997; Victoroff et al., 1998).

Caregiving rendered the caregiver more prone towards depression and stress (Rosenvinge et al., 1998; Victoroff et al., 1998; Zarit et al., 1998). A significant association was demonstrated between the demands of caregiving and health problems (Flaskerud & Tabora, 1998; LeBlanc, London, & Aneshensel, 1997), with caregivers experiencing more psychological and physical symptoms. According to Cummings et al. (2002), caregivers suffered higher rates of depression and physical illness and were prescribed medications at a higher rate than individuals who were not caregivers. A study by Schulz & Beach (1999) on caregiving and mortality found that elderly spousal caregivers who experienced caregiver strain had a mortality risk that was 63% higher than a control group.

Caregiver burden as perceived by diverse groups of people across the globe was the subject of several studies. Navaie-Waliser et al. (2001) conducted a study comparing White, Black and Hispanic caregivers' experiences. These authors found some commonalities across groups, e.g. long-term caregivers were more likely to report unmet

needs than their counterparts who had only been providing care for a short period of time, and that those who reported difficulty with caregiving were more likely to be providing more involved care. However, there were significant differences in care workload, difficulty with care provision, and having unmet needs across groups. Mui (1992) also found that African –American female caregivers experienced less caregiver burden than white female caregivers, and that they experienced fewer negative health consequences than Hispanic caregivers. All groups in this study were equally at risk for emotional strain but the African American female caregivers appeared to have better adaptive skills.

The experience of caregiver burden among caregivers in African countries was often exacerbated by financial constraints. Mushonga (2001) discussed this vicious cycle of expenses and burden, with each causing the other, and the cycle being ongoing. Increased caregiver burden was a drain on the financial resources that were available to the family while at the same time, the continued drain of these resources increased the perception of burden. A study of palliative care that was funded by the World Health Organization in several African nations (Ethiopia, Botswana, Tanzania and Uganda, and Zimbabwe) found that most patients with terminal illness (cancer or HIV/AIDS) and their families had common problems. The most significant of these were noted as scarcity of resources, financial constraints, and lack of social support (Sepulveda et al., 2003). This study also found that in most cases, the caregivers were mostly family members and relatives, but they did not possess adequate knowledge and skills to perform the caregiving role.

A qualitative study of 11 female caregivers in Canada (Sawatzky & Fowler-Kerry, 2003) found that caregiving had short term and long term effects on the caregiver

that included financial constraints and health concerns. In many cases, the patient was unable to work, and sometimes the caregiver had to give up their own employment in order to look after the patient. This was in addition to the added medical expenses incurred from the illness. Caregivers suffered from ill health and the demands of caregiving often compounded the health concerns of the caregiver. Navaie-Waliser et al. (2001) called for studies that specifically examined subgroups of caregivers in order to understand the unique challenges that faced each group of caregivers. The next section looks specifically at the experiences of caregivers of persons living with HIV/AIDS as documented in the literature.

Caregivers of PLWHA

HIV/AIDS infection rates were on the increase globally (CDC, 2004). The impact of HIV/AIDS was a subject that received a great deal of attention with much research being done to investigate how HIV/AIDS impacted the infected persons (Songwathana, 2001). However, little had been done to investigate the impact of HIV on persons who were caregivers of persons living with HIV (PLWHA). Most of the research focused on the medical aspects of HIV/AIDS while paying little attention to the mental health and psychosocial implications of the disease (Freeman, 2004). There was a need to look at the impact of HIV/AIDS not only on those who were infected, but also those who were affected by the disease. Hanson (2000) noted that as the HIV/AIDS epidemic continued to increase, the number of persons directly and indirectly affected also continued to rise because every infected individual represented a family system and social network.

Prachakul & Grant (2003) conducted a review and analysis of published empirical studies that examined the physical and psychosocial outcomes in caregivers of persons living with HIV/AIDS. This analysis only found 14 studies, most of which had male caregivers. This was chiefly because HIV/AIDS in the United States was initially associated with the gay community and most AIDS patients were in the care of their partners. This was much unlike the situation in Kenya where transmission was chiefly through heterosexual contact and where caregivers were chiefly female.

Existing literature on caregivers helped to shed light on the experiences of caregivers for persons suffering from various illnesses. Previous studies looked at caregivers for persons with dementia (Daire, 2004; Daire, 2001; Nunley, 2000; Onishi et al, 2005), Alzheimer's (Cummings et al., 2002; Martin-Cook et al., 2000), and strokes (Wyller et al., 2001). While information like this was helpful, the provision of care for a person infected with HIV/AIDS was complicated and differed from that of other medical conditions (Hendrick, 2000; Lesar & Maldonado, 1997). According to Hendrick (2000), providing care for persons living with HIV/AIDS was made more stressful by the uncontrollable nature of the symptoms, the disfiguring effects of the disease, anticipated loss and grief, as well as inadequate preparation for the role of caregiver. Persons with HIV/AIDS also tended to be younger than persons typically afflicted with illnesses such as Alzheimer's or strokes (Hendrick, 2000) and dealing with the loss of a loved one when they are at the prime of their life is more difficult to deal with. Findings from studies conducted with other populations were not necessarily applicable for caregivers of persons living with HIV/AIDS for several reasons.

Caregivers for a family member living with HIV/AIDS faced unique challenges due to the complicated nature of the illness (Stajduhar, 1998). The mode of transmission of HIV, the contagious nature of the virus, and the initial association of HIV/AIDS with marginalized groups served to impart a social stigma across the globe (Cargan & Ballantine, 2000; Powell-Cope & Brown, 1992) that extended to the caregivers. Bunting (2001) noted that AIDS related stigma often added to the work and grief of the caregiver and served to increase anxiety and stress by isolating the caregiver and the recipient from sources of support.

The manner of tasks that one performed as a caregiver for a person living with HIV/AIDS varied from helping with cooking, cleaning, bathing and dressing the patient, changing soiled linen, feeding, getting them in and out of bed, and administering medication (Mushonga, 2001) The degree to which one performed the above tasks depended upon the severity of the patient's illness. Caregivers for patients with lower functioning levels on activities of daily living (e.g. cooking, cleaning) reported higher levels of caregiver burden (Cooper et al., 2006; Wight, 2000). A study of 15 female caregivers in Malawi (Chimwaza & Watkins, 2004) found that the tasks of caregivers included the following:

preparing food and traditional medicines for the patient, feeding the patients and medicine, heating water and bathing the patient, cleaning sores, massaging and exercising (the patients') limbs, carrying patients who were immobile to the pit latrine or to sit on the sun, and washing soiled linen in a stream or in a bucket of water.

In most cases, the patients were too sick to be left alone and the caregivers had to be present to monitor them.

For caregivers of a person living with HIV/AIDS, social stigma increased perceptions of burden among caregivers (Powell-Cope & Brown, 1992). These authors referred to the stigma experienced by caregivers as a result of their association with the infected individual as guilt by association. In a qualitative study conducted among caregivers for a family member living with HIV/AIDS in Mumbai, India, (D’Cruz, 2004), participants reported experiencing social isolation as well as being stigmatized by their extended families and communities. This was important especially given that African societies were communal by nature and there would be a presumption that caregivers could expect and receive help from the extended family and their community. Indeed, the caregivers were reported to have become secondary targets of stigma because of their association with the infected person (Powell-Cope & Brown, 1992).

Olenja (1999) carried out a study with HIV patients in Kenya and found that persons living with HIV/AIDS and their caregivers experienced a sense of isolation and stigmatization from their larger community. When there was a deficit in social knowledge about HIV/AIDS, there was a higher likelihood that person with HIV/AIDS and those associated with them would experience social isolation and stigma. This had significant implications for coping strategies particularly because social support was identified in literature as a key coping strategy among caregivers (D’Cruz, 2004).

The unpredictability of disease progression was reported in previous research as a factor that further aggravated caregiver burden (Brown & Powell-Cope, 1991; Rutman, 1996; Stajduhar, 1998). In a qualitative study with female caregivers, Rutman (1996)

found that caregivers were frustrated by the unpredictability of caregiving. The ever changing physical and medical condition of the care recipient served to diminish the value of the work these caregivers performed, further making them uncertain about how to best provide care. In the case of HIV/AIDS caregivers, this was true especially because the symptoms and opportunistic infections of HIV/AIDS manifested in various ways, thereby requiring intensive and prolonged care (Bunting, 2001). Participants in a study of family caregivers (Brown & Powell-Cope, 1991) expressed uncertainty with 'roller-coaster' of HIV/AIDS and the instability it brought about.

Caregivers for a family member living with HIV/AIDS also had to deal with the fear of contracting the virus (Nkowane, 1993). This was true particularly where knowledge about HIV/AIDS and the modes of transmission was limited (Hansen et al., 1998). Even when caregivers had knowledge about transmission and were willing to take on the caregiving role, they often lacked the necessary resources such as gloves to protect themselves from infection during routine caregiving (Nkowane, 1994). Hansen et al (1998) found that caregivers did not have adequate knowledge about how to handle soiled clothes and they clearly needed training on how to care for a person with HIV/AIDS.

Hanson (2002) also noted that the demands of caregiving were often superimposed on the caregiver's own issues of emotional adjustment to the diagnosis for a loved one. Caregivers experienced a range of emotions as a result of watching a family member go through the different phases of illness. In a study of caregivers for patients with Alzheimer's, Onishi et al (2005) found that more than 25% of the caregivers interviewed experienced a strong sense of loss due to the deterioration of cognitive

function of the care recipient. This loss was similarly experienced by caregivers for a family member with AIDS. Indeed, because most HIV/AIDS patients were younger in age compared to the average Alzheimer's patient, the progression of disease was even harder to deal with (Hendrick, 2000).

An analysis of studies done with caregivers of persons living with HIV/AIDS in the United States identified some gaps in the literature in this area. Prachakul & Grant (2003) found a selection bias of participants in the reviewed studies with an over-representation of gay male caregivers. This analysis also identified a gap in the literature in examining the relation of caregiver burden to other variables related to caregiving, e.g. age, ethnicity, and duration of care. The authors called for more research in this area that would specifically examine caregiving outcomes in ethnic minority populations.

Research showed that home-based care for PLWHA was optimal because the infected person was able to remain in the environment that they were familiar with (Campbell, 2001). Most people preferred to be cared for at home (WHO, 2002), and the quality of life was improved by effective home based care. It was imperative that caregivers who provided home-based care to their loved ones with HIV/AIDS be provided with adequate support in order for them to provide the necessary care. This could best be accomplished if we gain a better understanding of the impact of the disease on caregivers and therefore make efforts to provide the kind of support that would ease the impact of HIV on the caregiver.

Female Caregivers

A review of studies conducted to investigate caregiver burden found that caregiving was often a task that fell to women (Bunting, 2001; D’Cruz, 2004; Linsk & Poindexter, 2000; Martire et al., 1997; Rutman, 1996). In a study of burden among caregivers for patients with dementia in Japan, 84% of the caregivers were female (Onishi et al., 2005). Studies on caregivers in Africa also found that the majority of caregivers were women (Chimwaza & Watkins, 2004; MacNeil, 1996).

Onishi et al. (2005) found that women caregivers were significantly more likely to provide more intensive and complex care, have difficulty with care provision and balancing caregiving with other family and employment responsibilities, suffer from poorer emotional health secondary to caregiving, and cope with caregiving responsibilities by engaging in increased religious activities. Gallicchio et al (2002) conducted an investigation into gender differences in burden and depression among informal caregivers of demented elders. Their study consisted of 327 informal caregivers, majority of whom were female. These authors found that a significantly higher percentage of women caregivers had a higher burden score than the male caregivers. The authors hypothesized that it was likely that women caregivers spent more time and effort in caregiving than their male counterparts in the study as was been the case in previous studies.

In addition to the fact that women in Africa were particularly vulnerable to contracting HIV/AIDS, the epidemic impacted them in many other ways. Women’s traditional role of caregiver meant that the primary responsibility of looking after AIDS patients and orphans fell to them (MacNeil, 1997). With the increased strain on the health

infrastructure, most AIDS care took place in the home, forcing women to take on additional duties of the caregiving role. Women therefore bore the brunt of HIV/AIDS caregiving (Bharat & Aggleton, 1999; D’Cruz, 2004). D’cruz (2004) noted that across the globe, women were oriented towards caregiving, and nurturing, a natural extension of their role as mothers. Songwathana (2001) observed that the role of women as family caregivers seemed to be both psychologically and socially constructed. Olenja (1999) observed that women were the most economically disadvantaged and yet they had to take on the burden of care for persons with AIDS. In Kenya, when the burden of care was relegated to the family, it was ultimately the women who carried the load and struggled to provide care with limited resources, information and skills. The term caregiver therefore often referred to women, with men becoming caregivers only when there were no women available to take on that role (Abel, 1991; Hooyman & Gonyea, 1995; Kaye & Applegate, 1990).

The UNAIDS Report (2004) noted that HIV had a particularly great impact on women and girls who bore the burden of care. The demands associated with caring for a family member that had HIV/AIDS were often in addition to their ordinary duties in the home. When a spouse was ill, often times the woman was also infected. In spite of this, she still had to continue providing care for her ailing spouse and care for the children, in addition to the normal household chores. Her own needs and health considerations came last (Campbell, 1999; D’Cruz, 2004). Bharat & Aggleton (1999) found that when wives were infected with the virus, they often neglected their own needs in order to first meet those of their children and their husbands.

In a study of rural women with HIV/AIDS, Walker (2002) concluded that the socialization of women into gender roles might impel women with HIV/AIDS to ignore their own health needs in order to meet the needs of others. Linsk & Poindexter (2000) also found that the women in their study were not concerned about their own health but rather were intensely focused on the health and well being of the person they were providing care for. Even when the women caregivers had health problems as was often the case, they only sought treatment or care for themselves as a last resort (Walker, 2002). Because of their primary role as caregivers and not as care recipients, when women were in the role of receiving care, they perceived themselves as a burden to their caregivers. Another study of HIV positive female caregivers by Hackl, Somlai, Kelly, & Kalichman (1997) found that the women were concerned primarily about AIDS related stigma, their children, social support, death and dying, and obtaining information about HIV. They faced isolation and stigmatization and expressed a need for social support.

Research conducted in Arusha, Tanzania with caregivers indicated that the burden of care in HIV/AIDS affected different generations of women (Godwin, 1998; Evans, 2005). In almost all cases where there was an infected child, it was almost always the case that one parent, often the mother was also infected. Mothers therefore provided care for their ill children in addition to meeting their developmental needs, as well as taking care of their own medical needs. Many women involved in caregiving were doubly burdened in that they were HIV-positive themselves. Women often had to take care of their children who were infected, and take on grandchildren who were orphaned by the deaths of their parents. These orphans might also be infected, and the tasks of providing care are continued with these children. Women also provided care for their spouses who

were infected. In such cases where both husband and wife were infected, it was often the wife who took on caregiving, often at the expense of her own health. In a study with HIV infected women who were also caregivers, Hackl et al. (1997) found that all the women exhibited signs of clinical depression.

It was little wonder therefore, that the phenomenon of women as caregivers for a family member that was living with HIV/AIDS in Africa had received such little attention in the literature perhaps because this was viewed as an extension of the duties that women performed. Indeed, caregiving depended on the work of women, who provided an unpaid (D’Cruz, 2004) and often unacknowledged service that complemented, and in many places, supplemented formal health care. Wight et al (1998) noted that the role of women in providing informal care tended to be minimized in discussions about how to minimize health care costs. While the burden of care was eased for the medical sector, the load was shifted to women.

In Kenya, this was especially observable in the trend towards home-based care with little consideration for who took on the care once it was off the shoulders of health institutions (Olenja, 1999). Linsk & Poindexter (2000) described this very aptly in their study of older minority caregivers for family members with HIV/AIDS. These authors discussed what they termed as ‘the tower of strength’ image that was often associated with caregivers of persons living with HIV/AIDS, and that was often at an unacknowledged cost to the caregivers. The next section will look at the experiences of caregivers in Kenya as documented caregivers in the literature.

Caregivers in Kenya

In reviewing the literature on caregivers, it is important to note that little had been written about caregivers in Africa. Existing literature that derived from studies in cultural contexts other than African can only be used tentatively when speaking about caregivers in Kenya. D'Cruz (2004) argued that cultural factors such as race, age, gender, and type of illness all play an important role on the experience of caregiver burden. Folkman et al. (1994) reported that there were significant differences in the experience of caregiver burden based on ethnicity. There were certain factors that further compound the caregiving role for persons living with HIV/AIDS in Kenya. The health care infrastructure in both urban and rural Africa was often insufficient to meet the demands of persons infected with HIV/AIDS (Amoroso et al., 2002). Additionally, the high cost of HIV/AIDS medication limited accessibility.

Although there existed a great deal of research on caregivers, much of the literature in this area treated caregivers as one homogenous group (Navaie-Waliser et. al., 2001). As a result, much of the information on caregivers was based on research that was not equally representative of minority groups (Dilworth-Anderson, Williams, & Cooper, 1999). Studies that examined differences among ethnic groups found that significant differences between ethnic minority caregivers and White caregivers (Knight, Merrill, McCallum & Fox, 2000; Miller & Snigdha, 1999). While the findings of these studies were key to understanding the plight of caregivers in the West, they could not be applied in the Kenyan context. Even those studies that did comparative analysis of informal

caregivers from different ethnic groups were found to have serious limitations that greatly hampered generalization (Navaie-Waliser et. al., 2001).

Caregivers for persons living with HIV/AIDS in Africa faced challenges that are unique to them. This was the result of a combination of factors. The lack of health care facilities and access to medication (Campbell, 2004) made the provision of care even more complex. Further, the majority of the population that provided home-based care for family members with HIV/AIDS did so with limited understanding of the disease and little support from the health care system (Olenja, 1999).

In a study carried out in Kiambu District in Kenya to assess community attitudes towards home based care for PLWHA, Olenja (1999) found that in spite of the government's efforts to push towards more home based care, there was reluctance on the part of the community to take on this role. This was chiefly due to as inadequacy of information about HIV/AIDS and how to care for infected persons, high stigma levels, and financial constraints that the families faced. This study also found that certain key elements such as counseling, social support, and care that were crucial to optimal home based care were lacking. The author concluded that there was a gap between the noble concept of home based care and the reality that was prevailing in Kenya.

Olenja (1999) also found that even when the families were very willing to take on the care, there were concerns that were the result of limited resources and means. Some viewed persons with AIDS as a financial burden to them and preferred that medical and other care be provided at a hospital rather than in the home. Some participants in this study reported that frequent illness episodes forced the family to incur huge medical expenses every time they had to take the person with AIDS to hospital. Caregivers

discussed their feelings of a moral obligation to provide care for a person who was dying even though they might prefer to keep them in hospital. Poverty was identified as a significant issue in the provision of care. There were concerns about physical space in the house to accommodate the sick person, and the author noted that the burden of home care was a trying experience for caregivers who were already battling with poverty.

An interesting observation that emerged in Olenja's study (1999) was that the persons that were ill appeared to expect more from their families than could be provided. They failed to understand that their becoming ill had not changed the economic state of their family for the better. Persons with AIDS had nutrition needs that exceeded family budgets, yet they demanded to have them. This could only serve to increase the frustration experienced by the caregivers, thereby exacerbating burden.

The role of stigma in exacerbating caregiver burden was well documented in the literature (Bunting, 2001; D'Cruz, 2005; Mushonga, 2001; Powell-Cope & Brown, 1992). In Kenya, there was still much shame and secrecy surrounding a diagnosis of HIV (Nzioka, 2000). The mode of transmission in Kenya was chiefly heterosexual sex and to contract the virus was taken as a sign of promiscuity or sexual irresponsibility (Olenja, 1999). The infected individual often tried to keep their condition secret and only disclosed to family members when the disease advanced to a symptomatic level. Even then, the family might try to hide and caregivers tried to give care in secrecy because they feared the consequences of disclosing. This need for secrecy heightened caregiver burden (Mushonga, 2001). Eventually, the family secret may be 'outed' when the patient began to show the tell-tale signs such as the massive loss of body weight and a darkening of the skin that was common among people with AIDS in black Africa (Mushonga, 2001).

Olenja (1999) also noted that the family structure in Kenya had undergone a great deal of transformation thereby eroding the sense of support from community and family that was a feature of African societies in the past. This study also found that the women in the family often felt stuck with the responsibility of care giving, providing care for a sick relative not out of their own volition but out of a sense of obligation. The burden of care was often assumed by single family members, contrary to common notions that community helped. With Kenyan societies being chiefly paternalistic (Nyambedha, 2003), women assumed the role of caregiving from an already disadvantaged position of being the social underlings compared to men. The interaction of social disempowerment and the challenges of providing care with limited resources was a subject that called for research. This next section looks at literature on female caregivers.

Coping responses

Coping refers to the actions that people take to avoid or to reduce the strain of life's problems (Lazarus & Folkman, 1984). Monat & Lazarus (1991) discussed the coping behaviors that individuals adapt as constantly changing as a result of changes within their specific context. The literature discussed different types of coping behaviors or responses. According to Lazarus & Folkman's coping model (1984), problem oriented coping responses attempt to manage the problematic situation while emotion-focused coping behaviors attempt to handle the emotions that the crisis evokes. Lazarus & Folkman (1984) defined problem focused coping as including strategies such as gathering information, decision-making, planning, and resolving conflicts that created distress. According to Lazarus & Folkman's theory of psychological stress and coping, problem-

focused coping engages the caregiver in weighing costs and benefits, generating solutions, and acting on these solutions. This is also sometimes referred to as confrontive coping. Emotion-focused coping is avoidance of the problem and it may be used to maintain hope and optimism and/or to deny the facts and what these facts may imply.

Some studies that examined caregiver burden found an association between burden and factors such as social support and coping strategies used by the caregiver (Parks & Pilisuk, 1991; Pratt et al., 1985). The ability of a caregiver or a patient to integrate into a social network and obtain resources from this network was significant in improving the health of the individual. Several studies found a relationship between social support as a coping resource and caregiver well-being (Knight et al., 2000; Pakenham, 2001). McCausland & Pakenham (2003) carried out a study to investigate the benefits of caring for a person with HIV/AIDS among 64 HIV/AIDS caregivers and 46 HIV positive care recipients in Australia. This study found that higher levels of social support were related to less depression and global distress among both caregivers and the care recipients. Self-blame and wishful thinking were significantly related to global distress.

While coping responses had been researched through the world, (Joseph & Bhatti, 2004; McCausland & Pakenheim, 2003; Pearce, 2005), the responses that research identified as most effective were effective in the context within which they were studied. Further, the coping responses that people used were a function of a combination of factors such as economics, culture, and personality. Folkman & Lazarus (1984) stressed that coping processes needed to be examined within the context of the stressful situation. They noted that stress was a relationship between the person and their environment as

appraised by the individual. This was an important consideration in discussing coping factors because coping factors must be seen in light of different environmental contexts. Differences in coping were associated with situational demands and constraints. This underscored the need for research that would look at specific populations within their unique environment.

Coping strategies were important predictors of caregiver well-being. A research study carried out with 126 caregivers of people with Alzheimer's disease investigated the relationship between coping strategies and caregiver anxiety (Cooper et al., 2006). Participants in this study were administered the Brief Cope and the Hospital Anxiety and Depression Scale. This study found that dysfunctional coping strategies and depression appeared to be important factors in predicting caregiver anxiety. The authors suggested that it would be helpful to address coping strategies in order to manage caregiver anxiety, an element that contributes to caregiver burden.

Research on coping strategies reported mixed findings about which coping strategies were associated with greater caregiver burden. The literature was more inclined towards approach coping as a more effective strategy in easing caregiver burden, and avoidance coping being related to higher levels of anxiety (Cooper et al., 2006) and depressive symptoms (Aranda et al., 2001). Brouwer et al. (2000) found that caregivers who did not accept their child's HIV status were not motivated to comply with advice given by the doctor or the counselor and were more unlikely to recognize the need for care.

Rose & Clark-Alexander (1999) examined coping styles and quality of life among nonparental caregivers for children with HIV/AIDS. Even though their sample size was

considerably small, (n=25) their findings were consistent with previous research that found most caregivers to use problem-focused coping strategies. The most common types of coping methods used were prayer and trying to maintain some control over the situation. Participants who utilized emotion focused coping strategies were more likely to experience depression and use alcohol and experienced lower quality of life than their counterparts who used problem focused coping strategies. This study also found that social support significantly impacted quality of life for the caregivers.

Coping responses among caregivers in western countries included accessing support from professionals such as counselors, as well as sharing information and obtaining support from family and friends (Sawatzky & Fowler-Kerry, 2003; Shields, et al., 1995; Stajduhar, 1998). Indeed, social support was identified in many studies of caregivers as a key coping resource (Folkman et al., 1994). In a grounded theory study of women caregivers (Bunting, 2001), many participants expressed a need for support from other family members, a support group or health professionals. For them, having this need met would serve as a key coping strategy in their role of caregiver. According to Stajduhar (1998), when caregivers were able to seek support, they were better able to implement caregiving strategies that helped them feel a sense of pride and find meaning in what they did as caregivers. However, accessing social support was often a complicated task for caregivers of a family member living with HIV/AIDS. This was often because seeking social support led to disclosure of what many preferred to keep as a closely guarded family secret (Powell-Cope & Brown, 1992). In Kenya, the social stigma that surrounded HIV/AIDS acted as a barrier to seeking social support (Nzioka, 2000).

A study conducted with HIV/AIDS patients with Hemophilia found that the most common types of coping responses used by the participants were maintaining personal and social relations, obtaining information about the disease and its management, and planning for the future (Stewart, Hart & Mann, 1995). Respondents considered information about support groups to be very important. An earlier study conducted with caregivers of children infected with HIV (Mellins & Ehrhardt, 1994) found that the most frequently reported coping strategies included acceptance, distraction, self-reliance, and religion

Another key coping factor that research on caregivers identified was religiosity (Folkman et al., 1994; Tolliver, 2001). Picot (1995) found that religion was considered the most helpful form of support among caregivers of persons with dementia. In their study of White, Black and Hispanic caregivers, (Navaie-Waliser et. al., 2001) found that Black caregivers were more likely to experience increased religiosity after they took on the role of caregivers. In a study of Black family caregivers of a family member with dementia, Segall & Wykle (1988) found that more than 60% of the respondents rated prayer, faith in God and religion as their number one coping strategy. Religiosity was therefore found to be a potential coping strategy that Blacks employed to help them deal with the demands of care provision. Mellins & Ehrhardt, (1994) also found that religion was the most useful coping strategy among 31 families of children infected with HIV/AIDS.

Davis (1998) noted that in spite of a plethora of research that focused on HIV/AIDS and treatment interventions, there existed little that was related to the psychosocial needs of caregivers and their coping behaviors. This author further identified a need for studies

validating instruments in distinct caregiver group subsets in order to assist in the provision of optimum functioning and health. Stajduhar (1998) decried the lack of adequate research on coping responses among caregivers of a person living with HIV/AIDS and called for more research that would target caregivers' needs and their perceptions of what kinds of support would be helpful for them.

Caregivers for PLWHA in Kenya provided care in the absence of the coping resources that caregivers in western countries had available to them. Olenja (1999) noted that caregivers in Kenya lacked training about how to care for AIDS patients and did not have counseling and social support, both important prerequisites for home-based care. The economic situation also factored into the provision of care because a diagnosis of HIV for a family member in Africa had serious financial implications (Mushonga, 2001). If the infected family member was a sole breadwinner, the family had to find alternative sources of income. The duties of caregiving also greatly interfered with work and income generating activities for the rest of the family, as time was taken up in caring for the infected person.

Folkman (1997) suggested a revision of the coping model to include positive psychological states of the caregivers. This would be of particular interest to the current study, particularly in light of discussions of resiliency in African women faced with tremendous adversity (Evans, 2005) In a study with male caregivers of a partner with AIDS, Folkman (1997) identified four types of coping processes that were associated with positive psychological states during caregiving and bereavement: positive reappraisal, goal-directed problem-focused coping, spiritual beliefs and practices, and the infusion of ordinary events with meaning. The author also suggested that all the above

coping processes had the common theme of searching for and finding positive meaning and called for more research into personal characteristics that might predispose people to positive psychological states in the coping process.

There was increased interest in the role of positive psychological and emotional states in the coping literature (Folkman, 1997; Hooker et al., 1992). Scheier et al. (1989) found that dispositional optimism was related to coping in persons recovering from coronary bypass surgery. Hooker also suggested that personal characteristics such as optimism may help to protect the caregiver from some of the negative consequences of caregiving. In a study of spousal caregivers for a patient with Alzheimer's, Hooker et al. (1992) found that optimism was directly related to depression and psychological wellbeing of the caregivers.

Evans (2005) conducted an ethnographic study with children and families that were affected by HIV/AIDS in Tanzania. This author discussed the implications of a social resiliency perspective on the development of interventions to work with the population that was affected by HIV/AIDS. In examining children who had been impacted by HIV/AIDS, Evans (2005) found that these children showed considerable resiliency in negotiating vulnerability and coping with the impacts of the HIV/AIDS epidemic. Interviews with parents, caregivers and children with HIV/AIDS supported the approach of identifying people's coping strategies and agency to build upon in designing and implementing interventions. This author called for recognition of the coping strategies that people already utilized, citing these as a crucial framework for the design and implementation of interventions.

In another study conducted among 75 female caregivers who occupied multiple roles to investigate feelings of role mastery as predictors of self esteem, Martire et al. (1997) reported that a striking finding of the study was how caregiving was potentially beneficial to the caregivers. This study found that caregiving offered opportunities for women to experience a feeling of adequacy. Women who perceived that they had mastered the challenges of caregiving were likely to experience more satisfying relationships with family members. These findings supported the notion that feeling effective as a caregiver may improve the caregiver's mental health.

Summary of the literature

This review presented an overview of the relevant literature in the areas of HIV/AIDS in Africa and Kenya in particular, caregivers for PLWHA, caregiver burden, and coping strategies. Research on the experiences of caregivers demonstrated adverse effects of caregiving on the caregiver's emotional, physical and social wellbeing (Folkman et al., 1994; Powell-Cope & Brown, 1992; Zarit et. al., 1990). A review of the literature demonstrated that there were mixed findings about the characteristics that led to reduced or increased caregiver burden among caregivers for a family member that was living with chronic or terminal illness. This was even more so for caregivers for a family member that was living with HIV/AIDS because of many social connotations of HIV/AIDS and related stigma. The review also indicated a wide gap in knowledge about the experiences of family caregivers in Kenya, with particular reference to those who were caring for an individual that has AIDS.

Although there was a consensus in the literature that caring for a family member that was unwell placed significant burden on the caregiver, there were mixed findings about how some significant factors impacted the experience of caregiver burden. Different studies identified varying demographic characteristics to be predictors of burden (Folkman et al., 1994; Mushonga, 2001; Onishi et al., 2005; Pakenham et al., 1995; Powell-Brown & Cope, 1992). The literature on this was found to be inconclusive and called for studies that addressed specific populations. There was also limited understanding of the coping responses that caregivers for a family member that was living with HIV/AIDS found to be effective in mediating caregiver burden. Studies conducted in this area had been conducted in the United States, Europe and Canada.

Existing research in this area pointed to the need for studies that would help to foster greater understanding of the experiences of caregivers and the challenges that caregivers from different populations were faced with (Navaie-Waliser et. al., 2001). Studies also called for research that facilitated the development of culturally sensitive programs and policies that would help meet the ever-changing needs of caregivers in their diverse settings.

CHAPTER 3 METHODOLOGY

This study was an exploration of caregiver burden and coping responses among female caregivers for a family member living with HIV/AIDS in Kenya. The study set out to identify significant coping response factors in female caregivers for a family member that is living with HIV/AIDS in Kenya. The study also sought to investigate the relationships that existed between coping response factors and caregiver burden in female caregivers for a family member that is living with HIV/AIDS in Kenya.

The analyses conducted investigated coping response factors among the population of the study as measured by the Brief Cope (Carver, 1997) and the level of perceived caregiver burden as measured by the Zarit Caregiver Burden Inventory (Zarit et al., 1980). This chapter describes the procedures that were used to identify participants and to collect data. The chapter also contains a description of the instruments that were used in the study, discusses the specific hypotheses that were investigated, describes the variables for each hypothesis, and the methods of data analysis that were used for each hypothesis.

Research Questions and Hypotheses

This study investigated two research questions in order to identify coping response factors among female caregivers for a family member that is living with HIV/AIDS in Kenya as well as examine the relationship between coping factors and perceived caregiver burden.

Research Question A and Hypothesis

What are the underlying factors among coping responses in female caregivers for a family member that is living with HIV/AIDS in Kenya?

Hypothesis 1: A factor analysis of the Brief Cope (Carver, 1997) will produce five significant coping factors among female caregivers for a family member that is living with HIV/AIDS in Kenya.

An exploratory factor analysis was undertaken to identify coping factors from the Brief Cope for the population of the study. A principal component analysis with varimax rotation was run on the 14 scales of the Brief Cope to identify key factors that loaded at an Eigenvalue of 1.

Research Question B and Hypothesis

What relationships exist between coping response factors and caregiver burden in female caregivers for a family member that is living with HIV/AIDS in Kenya?

Hypothesis 1: Coping factors derived from the factor analysis of the Brief Cope will be significant predictors of caregiver burden among female caregivers for a family member that is living with HIV/AIDS in Kenya.

A multiple regression was run to determine whether caregiver burden could be predicted based on the coping responses that an individual uses. The independent variables were the coping response factors identified in the investigation of hypothesis 1 and the dependent variable was perceived caregiver burden as measured by the Caregiver Burden Inventory (Zarit et al., 1990).

Population

The target population for this study consisted of female caregivers for a family member that was living with HIV/AIDS in Kenya. It was expected that caregivers would vary in age, relationship to the care recipient, living arrangements and economic status.

Criteria for inclusion in the study were:

1. The individual identified as the primary caregiver for a family member that was living with HIV/AIDS. The caregiver lived with the care recipient under the same roof or resided in close proximity to the care recipient. The caregiver had personal contact with the care recipient.
2. The caregiver was an informal caregiver. This meant that the caregiver did not receive remuneration for the work they did as a caregiver and did not provide care as a means to earn a living.
3. The caregiver was 18 years or older. One exception was made with a caregiver who was 14 years old but met all the other criteria. Parental consent was obtained from this participant's mother who was the care recipient.

Participants

Participants for this study were identified by means of a non-random purposive sampling procedure. This design was necessary because of the anticipated difficulties in reaching this population. The primary sampling unit consisted of AIDS agencies and medical care facilities in three of Kenya's eight provinces, namely, Nairobi Province, Central Province, and the Rift Valley Province. The researcher contacted these agencies and sought permission to access the population that was served by the respective agency.

In Nairobi province, three agencies were contacted, namely, Mbagathi District Hospital HIV Clinic, Kenya Network of Women with AIDS (KENWA), and Women Fighting AIDS in Kenya (WOFAK). Upon receiving permission from the agencies, the researcher identified an individual who would assist in distributing the packets and reading the invitational letters to caregivers who were not literate. The researcher obtained permission from KENWA and the Korogocho Office of WOFAK. There was no response from Mbagathi District Hospital HIV Clinic. In the Rift Valley and Central Provinces, contact was made through extension field officers who were affiliated with local hospitals. In Rift Valley, packets were also distributed at a meeting of caregivers with the permission of the area chief.

The sample in this study consisted of 116 female caregivers who were providing care for a family member that was living with HIV/AIDS in Kenya. Participants were distributed as follows: 66 participants from Nairobi Province, making up 56.8% of the total participants, 33 participants from Central Province, making up 28.4% of the participants, and 17 participants from Rift Valley Province, representing 14.7% of the total participants. Responses of the participants on the demographic variables were

grouped into categories. Frequencies and percentages of sample composition and the demographics of these participants are presented in Table 3.1 and 3.2.

The participants in this study ranged in age from 14 to 80 years old. The average age of caregivers was 35 years (mean = 35.75). A total of eight four respondents were aged between twenty years and forty years of age. There were 41 respondents (35.3%) aged between 21 and 30, and forty three respondents (37.1%) aged between 31 and 40 years. The care recipients ranged in age from 1 year to 74 years old. The average age of the care recipients was 31 years (mean = 31.36). The largest number of care recipients were aged between 21 years and 40 years with 35 individuals (30.2%) between ages twenty one and thirty, and another 35 (30.2%) between thirty one and forty. Fourteen of the care recipients were pediatric HIV/AIDS with children under the age of ten years. More than eighty seven percent (87.9 %) of the respondents reported a monthly household income of 5,000 Kenya shillings or less (approximately \$75 US dollars), with about 50% having a monthly household income ranging between Kenya Shillings 1000 to 5000. About a quarter of the respondents (23.3% reported a monthly household income of less than 1000 Kenya Shillings.

Education levels for the participants ranged from no formal education at all, to some years in college. There were two modes for the education level, 8 and 9. These represent the number of years in school and would indicate completion of primary school. The two modes most likely result from a change in Kenya's education system in 1985 from the 7-4-2-3 British system of education (seven years in primary school, four years of ordinary level education, 2 years of advanced level education, and three years in university) to the American 8-4-4 system of education (eight years in primary school,

four years in high school, and four years in university. More than half of all participants had only a primary school education (58.9%). Five percent (5%) had less than 2 years of schooling (Table 3.1).

There were between two to eleven persons living in the households of the caregivers that were interviewed. Fifty of the respondents (43.1%) had two to four persons living with them while another fifty nine (50.9%) had five to eight people living in their household. as an average of six people in the households of the caregivers (mean = 5.16). Caregivers had provided care for an average of twenty four months. Twenty four caregivers (20.7%) had been providing care for a period of less than 6 months. There were twenty nine caregivers (25%) who had provided care for a period of 6 to 12, and the 36 (31%). The duration of care ranged from 1 month to 120 months (Table 3.2).

Sixty of the participants (51.7%) reported they were HIV positive, 32 participants (27.6 %) reported they were HIV negative, and the remaining 24 participants (20.7%) did not know their HIV status. Over 60% of the caregivers were caring for one family member with HIV/AIDS, while 23.3% were providing care for two or more family members living with HIV/AIDS. Thirteen participants (11.2%) were caring for a spouse, 10 (8.6%) participants were caring for a parent, 27 participants (23.3%) were caring for a son or daughter and 20 participants (17.2%) were caring for a sibling. Table 3.2 presents these number.

While findings of this study will be a useful primer in understanding the experiences of caregivers in Kenya, statistical inferences from this study will be limited to the sample used here.

Table 3.1

Demographic Characteristics of the Female Caregivers: Age of Caregiver, Age of Care Recipient, Number of Years in School, Monthly Household Income and Number of Persons Living in Household

Variables		Frequency	Percentage	Range
Age of caregiver	0-10	0	0	
	11-20	4	3.4	
	21-30	41	35.3	
	31-40	43	37.1	14-80
	41-50	12	10.3	
	51-60	11	9.5	
	61 and above	5	4.3	
Age of care recipient	0-10	14	12.1	
	14-20	8	6.9	
	21-30	35	30.2	1-74
	31-40	35	30.2	
	41-50	14	12.1	
	51-60	6	5.2	
	61 and above	4	3.4	
Number of years in school	< 2	6	5.2	
	3-8	57	49.1	
	9-13	25	21.6	0-16
	>14	19	16.4	
	Missing	9	7.8	
Monthly Household Income (KSh.)	Less than 1000	27	23.3	
	1001-2500	30	25.9	
	2501-5000	30	25.9	
	5001-7500	8	6.9	300-20000
	7501-10000	3	2.6	
	Above 10000	1	.9	
	Missing	17	14.7	
Number of persons living in household	2-4	50	43.1	2-11
	5-8	59	50.9	
	9-12	7	6	

Table 3.2

Demographic Characteristics of the Female Caregivers: Duration of care, number of persons the caregiver is providing care for, HIV status of caregiver, & relationship to the care recipient

Variables		Frequency	Percentage	Range
Duration of care (months)	<6 months	24	20.7	1-120
	6-12	29	25.0	
	13-24	36	31.0	
	25-36	9	7.8	
	37-48	7	6.0	
	49-60	5	4.3	
	>60	6	5.2	
# of persons CG is caring for	1	71	61.2	1-6
	2	28	24.1	
	3	8	6.9	
	4	4	3.4	
	5	3	2.6	
	6	2	1.7	
HIV Status of caregiver	Positive	60	51.7	
	Negative	32	27.6	
	Don't know	24	20.7	
Relationship to care recipient	Spouse/significant other	11.2	11.2	
	Parent	10	8.6	
	Son/Daughter	27	23.3	
	Sibling	20	17.2	
	Relative	46	39.7	

Procedures

The process of data collection took place over an eight week period beginning in October 2005 until November 2005. The researcher contacted a number of clinics and AIDS agencies that provided services to persons living with HIV/AIDS. At each location, the researcher identified a contact person and scheduled a meeting with him/her. The contact person was briefed about the purpose of the study and what procedures were involved. The process of informed consent was explained and its significance in the integrity of research was clearly explained.

Study packets were given to the contact person to distribute to caregivers that were affiliated with the respective agency. In many instances, the packets were to be distributed by home-based health care workers or counselors who made occasional home visits to persons living with HIV/AIDS. The contact persons were instructed to read the invitational letters to those caregivers who were not literate and invite them to participate in the study.

Due to the sensitive nature of the study and issues related to confidentiality, the caregivers were asked to initiate contact with the researcher in order to express their interest in participating in the study. A phone number was provided in the invitational letter so that those who had access to a phone could call the researcher to express their interest in participating in the study. Those that did not have a phone were asked to sign the invitational letter as an expression of their willingness to participate in the study and were asked to meet the researcher at a prearranged time at the same location where they obtained the packet. This was made necessary by the nature of the locales where the caregivers lived.

In Nairobi province, caregivers were contacted through KENWA and WOFAK. Both of these agencies had drop-in centers in various slum areas in Nairobi. It was deemed that obtaining physical directions to a caregiver's home would be a near impossible task in an area that is predominantly marked by alleys. As a result, it became necessary to identify a central place at each location where the interview would be conducted. The drop-in centers were used as meeting locations and the interviews were conducted here. Three KENWA drop-in centers were used namely, Mathare, Soweto, and Korogocho. One WOFAK drop in center was used, namely Korogocho. In Central Province and Rift Valley Province, the process was somewhat easier because it was easier to obtain directions. However, participants were scattered over large areas as compared to Nairobi where concentration rates were high in the areas selected for this study.

The study packets also contained a letter of informed consent as well as copies of the instruments that were to be used. These instruments were a researcher designed Demographic Questionnaire, the Caregiver Burden Inventory (Zarit et al., 1980), and the Brief COPE (Carver, 1997). At a time agreed upon in the initial contact, the researcher met with each participant and conducted oral interviews. This was done for all participants, including those that could read and write in order to ensure that the interviews were conducted in a uniform manner.

The researcher began by asking participants what language they preferred to use for the interview, Swahili, English, and Kikuyu. Based on their response, the researcher then proceeded to go over the informed consent with the participants in the language that they understood best. The researcher was accompanied by a witness who ensured that the

informed consent process was followed accordingly. The role of the witness was explained at the onset of the interview and participants were asked if they had any objections to having a witness at the interview. In all the interviews, none of the participants objected to having a witness. The letter of informed consent contained a request to audio record the interviews, with a designated place on the letter for the participants to sign as an indication of their approval. However, many participants expressed concern about being tape recorded and appeared to be suspicious of the process. Consequently, the researcher made the decision not to tape record any of the interviews.

The researcher proceeded to administer the instruments, beginning with the demographic questionnaire, followed by the Caregiver Burden Inventory. The Brief Cope was the final instrument to be administered. Participants were free to stop the researcher in order to ask any questions, or if they felt uncomfortable at any point during the interview. The participants were also free to not respond to any of the questions if they chose to. Participation was voluntary. Each participant was given 150 Kenya Shillings in appreciation for their time and the researcher explained that this money would be given regardless of whether or not the participant chose to discontinue in the course of the interview.

The researcher maintained full responsibility for the distribution and administration of the instruments in this study. Standardized procedures were used following the outline provided to, and approved by the Institutional Research Board at the researcher's university. Every effort was made to ensure that all participants received the same information and that data was collected in a uniform format.

Instrumentation

Instrument selection and design involved a thorough review of relevant literature with the goal of identifying demographic variables that would be relevant to this study as well as instruments that would be most appropriate for use with the target population to obtain the information that was sought in this study. The researcher gave consideration to cultural issues that might impact data collection and selected instruments that would be most congruent with the cultural environment. Three instruments were used to collect relevant data for this study. These consisted of a researcher-designed demographic questionnaire, the Caregiver Burden Inventory (Zarit, et al., 1980), and the Brief Cope (Carver, 1997). All instruments were translated into Swahili and Kikuyu and administered to the participants in their preferred language. The procedures followed for translation are discussed in a separate section.

Demographic Questionnaire

The first instrument was a researcher-designed demographic questionnaire. This questionnaire consisted of 10 items that sought to obtain information about the participants and their care recipients. The demographic variables that are included in this survey include the age of the caregiver, relationship to the care recipient, education level, duration of care, and household income. The variables that this instrument sought to obtain were guided by previous studies on caregivers. Research has been inconclusive about the demographic variables that impact caregiver burden and the findings are mixed. In a study conducted with a Turkish population, Karlikaya, Yukse, Varlibas & Tireli (2005) found that the caregiver's relationship to the care recipient had an impact on the level of burden experienced. Other variables such as age of care receiver (Karlikaya et

al., 2005), severity of the patient's symptoms, and duration of care (Onishi, et al., 2005) were found to be related to caregiver burden. Folkman et al. (1994) found that ethnicity, income level, and social support were all significant factors in the perception of burden among caregivers of men with AIDS. The demographic questionnaire sought to obtain information about the care recipient's age and their level of functioning as indicated on a measure of activities of daily living that was incorporated into this questionnaire. The five items on activities of daily living asked participants to indicate the level of functioning on a scale of 1 to 4 of the care recipient in the areas of walking, bathing, dressing, getting in and out of bed, and toileting. Several studies have found that the level of instrumental needs of the care recipient had a significant impact on the level of caregiver burden perceived (Cooper et al., 2006; Pakenham, Dadds, & Terry, 1995; Wight, 2000).

Caregiver Burden Inventory

To measure the level of perceived burden, the study used the Zarit Caregiver Burden Inventory (Zarit, Reever & Bach-Peterson, 1980), a 22-item scale that is one of the most widely used tools in the study of caregivers (Parks & Novielli, 2000). Indeed, the Zarit Caregiver Burden Inventory remains the most consistently used measure of caregiver burden in studies of caregivers for persons with dementia (Cummings et al., 2002). The items were derived from clinical and research experience with dementia caregivers and they have high content validity. The Zarit Caregiver Burden Inventory has high internal consistency and good test-retest reliability (Gallagher, Rappaport, Benedict et al. 1985; Hebert, Bravo, & Preville, 2000). Additionally, respondent ratings of

caregiver burden obtained from the Caregiver Burden Inventory were judged to be fairly reliable for the caregivers to whom it was given with a reliability coefficient of .88.

The 22-item Zarit Caregiver Burden Inventory has been translated and validated in French (Hebert et al., 2000;1993). This instrument has also been translated for use in languages such as Japanese (Onishi et al., 2005; Takahashi, et al., 2005), and Spanish (Gutierrez-Maldonado et al., 2005).

This instrument provides a single summary measure of the caregiver's appraisal of the impact caregiving has had on their lives. Participants are provided with a 5 point Likert scale ranging from 'never' to 'nearly always' and they select the response that best describes how they feel when taking care of another person. The numbers for the responses are added to obtain a total score that ranges from 1 to 88. The total score indicates the level and severity of burden perceived (0-20 = little or no burden, 21-40 = mild to moderate burden, 41-60 = moderate to severe burden, 61-88 = severe burden. The total score on the Caregiver Burden Inventory was the dependent variable in this study.

A review of existing literature found no instances of the Zarit Caregiver Burden having been used with any caregivers in Africa. Although the Zarit Caregiver Burden Inventory has been widely used in Europe and the United States, its use in developing countries has been fairly limited (The 10/66 Dementia Research Group, 2004). No translations of this instrument into Swahili or Kikuyu were known to have been in existence at the time of this study.

Brief COPE

The Brief Cope (Carver, 1997) is an abridged version of the 60-item Cope Inventory that was developed by Carver, Scheier, & Weintraub (1989). The Brief COPE

was developed based on concepts of coping from Lazarus and Folkman (1984). There are 28 items on the Brief Cope, with two items making up one of fourteen scales of coping, namely, self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame. Participants are required to rate the degree to which they use each coping strategy to deal with a particular stressful event. Ratings are made on a 4-point Likert-type scale that ranges from "I haven't been doing this at all" (1) to "I've been doing this a lot" (4). The Brief Cope contains items that look at different types of coping responses encompassing what the literature refers to as affective or emotion focused strategies/responses, and problem focused strategies/responses. Coolidge et al. (2000) grouped the subscales on the Brief Cope into three groups, emotion focused strategies, problem focused strategies, and dysfunctional strategies. The Brief Cope was validated with a sample of 168 participants that were survivors of Hurricane Andrew in the United States and has good psychometric properties with alphas ranging from .50 to .90. Respondent ratings of coping responses on the Brief Cope were judged to be fairly reliable for the population of caregivers in this study, with a reliability coefficient of .69.

The Brief Cope has been used in research with various populations. Badr (2004) used the Brief Cope in a study that investigated the role of gender and health on marital adjustment in married couples. The Brief Cope was used in a study to investigate how internet health information use was related to coping among breast cancer patients (Fogel, 2004). Meyer (2001) also used the Brief Cope to study how symptom severity,

social functioning and psychological well-being relate to coping among patients with schizophrenia.

Two studies with persons recently diagnosed with HIV/AIDS in South Africa used the Brief Cope to assess ways of coping among this population (Olley et al., 2004; Olley et al., 2005). Olley et al. (2005) investigated post-traumatic stress disorder with HIV/AIDS patients in South Africa. These authors conducted a factor analysis and extracted five coping factors from the Brief Cope for this population.

The Brief Cope has been used in many studies because of its ease of administration and reduced administration time burden. The Brief Cope has also been translated into several languages such as French (Muller & Spitz, 2003) and Spanish (Perczek et al., 2000). In abbreviating the COPE inventory to come up with the Brief Cope, the authors followed strong loadings from factor analyses of the original Cope Inventory. A review of the literature found no studies that had used the Brief Cope with a Kenyan population. There were no known existing Swahili or Kikuyu versions of the Brief Cope.

The author of the Brief Cope recommends that researchers adapt the instrument as needed for their own use. The author also states that there is no overall score on this instrument and suggests that researchers create second order factors using their own data to determine the composition of these factors. For this reason, some items on the Brief Cope were reverse coded to reflect what may be seen as maladaptive coping behaviors. Scales whose items were reverse coded were self-blame, substance use, behavioral disengagement, and denial. A factor analysis was deemed to be the best method of data analysis so that the researcher could identify more general patterns of coping among the

target population. Trial runs of the factor analysis with items reverse coded were run against items that were all coded similarly. The two factor analyses yielded the same factors, with the only difference being negative values in the alpha coefficients.

Translation of Instruments

All instruments were translated into two languages, Swahili and Kikuyu. There are over fifty (50) languages spoken in Kenya. Swahili is the national language and most Kenyans speak a native language and Swahili as well. The two languages were chosen because of the locations where the study would take place. Kikuyu is the predominant language in Central Province and the area of the Rift Valley Province where the study was conducted. Swahili was also selected because it is Kenya's national language and the unifying language between tribes. It was expected that most participants drawn from Nairobi Province would speak and understand Swahili.

The researcher conducted a preliminary review of instruments that have been used to measure burden as well as those used to examine coping. None of the instruments found had been validated for use with African populations. The researcher selected instruments that would oppose the least complexities in translation. The final instruments were the Brief Cope and the Zarit Caregiver Burden Inventory.

For each of the three instruments, the researcher put together two teams of individuals who were fluent in each language, namely, Swahili and Kikuyu. In the initial meeting, the teams reviewed the English instruments to be sure that they understood what each instrument aimed to obtain. Further, the teams discussed each item on the instruments to obtain clarity. Each team was divided into two groups, one of which would translate from English to Swahili or Kikuyu, and one of which would back translate the

first draft back to English. The final draft of each instrument was then given to a linguistic expert in each language and these persons were asked to check the translated questionnaires for validity and clarity of items.

There was difficulty in translating concepts from English to Swahili and Kikuyu. This complexity arose from the very onset, with questions about how to refer to the caregiver and the care recipient in Kikuyu and Swahili. The Swahili phrase that was used '*watoa huduma*' to refer to caregivers implies a person who delivers a service. This was the closest translation to caregiver. In Kikuyu, the same difficulty arose and it was decided to refer to the caregiver as '*murori wa muruaru*' a phrase that translates into 'the one who looks after the patient'. In the demographic questionnaire for instance, the activities of daily living required the respondents to indicate to what extent the care recipient needed help or supervision in various activities. The second option 'needs supervision' translated to Kikuyu as 'needs to be watched'. The last option 'needs total help' translated into Swahili and Kikuyu as 'is unable/cannot'.

All the Kikuyu instruments refer to the care recipient as *muruaru*, a Kikuyu word for 'the one who is sick'. Efforts were made to refrain from language that portrayed the persons living with HIV/AIDS as victims but this proved to be challenging due to linguistic considerations. In the Caregiver Burden Inventory, some concepts such as privacy as addressed in item 11 and control in item 17, posed complexities in translating.

Items in both the Caregiver Burden Inventory and the Brief Cope hold distinctions that are so subtle as to almost be lost in translation. For example, in the Caregiver Burden Inventory, items 20 (do you feel you should be doing more for your relative?) and 21 (do you feel you could do a better job in caring for your relative?) were repetitive in the

translated instruments. In the Brief Cope, the questions for each of the fourteen (14) scales were so closely related that in translating, it was difficult to make distinctions. Item 4 for example (I've been using alcohol and other drugs to make myself feel better) and item 11 (I've been using alcohol and other drugs to help me get through it) were very similar when they were translated. Other questions that posed this problem were item 3 (I've been saying to myself 'this isn't real) and item 8 (I've been refusing to believe that it has happened); item 18 (I've been making jokes about it) and item 28 (I've been making fun of the situation); and item 6 (I've been giving up trying to deal with it) and item 16 (I've been giving up the attempt to cope).

Research Design

There were two overall goals in this study. One was to identify underlying coping response factors on the Brief Cope (Carver, 1997) among female caregivers for a family member that is living with HIV/AIDS in Kenya and the second goal was to investigate the relationship between coping factors and perceived caregiver burden. Factor analysis is an advanced correlation analysis of the data whose goal is to discover if the observed variables can be explained largely or entirely in terms of a much smaller number of variables called factors (Smith & Glass, 1987). This procedure was used to investigate the first hypothesis and answer the first research question. The identity of each factor is determined after a review of which items correlate the highest with that factor. Items that correlate the highest with a factor define the meaning of that factor. The principal components analysis procedure was used to extract the factors from the variable data. A latent root criterion was used to determine which factors to extract (Hair et al., 1998).

This criterion requires that each given factor must be capable of explaining at least the equivalent of one variable's variance in order to be retained for interpretation.

A multiple regression was used to investigate the second hypothesis and answer the second research question. Regression analysis is a process of data analysis that uses the correlation between two variables to predict one from the other (Smith & Glass, 1987). Multiple regression analysis investigates whether one dependent variable can be predicted based on two or more independent variables. The second hypothesis sought to predict caregiver burden based on coping response factors by means of a multiple regression.

Variables

Variables for this study were selected based on a review of the literature in the areas of caregiver burden and coping factors. The Brief Cope consisted of twenty eight items. These items were further divided into fourteen scales, with two items contributing to each scale. Five factors were extracted from these scales by means of a factor analysis.

Independent variables

Coping response scores: These were obtained after a factor analysis of the responses on the Brief Cope (Carver, 1997) to extract 5 coping factors for the participants in this study. The Brief Cope consists of 28 items that fall under 14 scales. A data reduction procedure was undertaken by means of a factor analysis with varimax rotation to extract coping factors that best explained the coping responses among this population. The responses on the items that contributed to each of the five factors were summed to obtain a total score on the five factors. This total score on each of the five factors

extracted by the factor analysis became the independent variable against which caregiver burden prediction would be investigated.

Dependent variables

Caregiver Burden: The perceived caregiver burden was obtained from the Caregiver Burden Inventory (Zarit, et al., 1980). The total score was obtained by totaling the values that corresponded with the responses on each item of the Caregiver Burden Inventory. A Caregiver Burden Total score was obtained and became the dependent variable in the second hypothesis. This variable was used in the analysis to investigate whether coping response factors can be used predictors of caregiver burden.

Data Analysis

The Statistical Package for the Social Sciences (SPSS) was used to conduct the analyses. A basic descriptive statistics test was run to obtain frequencies on the demographic variables. Factor analysis and multiple regression were conducted to investigate the two hypotheses as described below.

Research Question A

What are the underlying factors among coping responses in female caregivers for a family member that is living with HIV/AIDS in Kenya?

Hypothesis 1: A factor analysis of the Brief Cope (Carver, 1997) will produce five significant coping factors among female caregivers for a family member that is living

with HIV/AIDS in Kenya. The Brief Cope consists of fourteen scales, each of which is made up of two items. The scales on the Brief Cope are as follows:

- Self-distraction: Items 1 and 19
- Active coping: Items 2 and 7
- Denial: Items 3 and 8
- Substance use: Items 4 and 11
- Use of emotional support: Items 5 and 15
- Use of instrumental support: Items 10 and 23
- Behavioral disengagement: Items 6 and 16
- Venting: Items 9 and 21
- Positive reframing: Items 12 and 17
- Planning: Items 14 and 25
- Humor: Items 18 and 28
- Acceptance: Items 20 and 24
- Religion: Items 22 and 27
- Self-blame: Items 13 and 26

Participants' responses for each scale were obtained by summing the responses on the two items that made up each scale. Item responses on four scales that were considered to be dysfunctional coping responses were reverse-coded, namely, self-blame, substance use, behavioral disengagement, and denial (Cooper et al., 2005). A principal component factor analysis with varimax rotation was run for the fourteen scales. Promax rotation was considered for this procedure. However, because the factors extracted from the factor analysis were to be used as independent variables in a multiple regression, varimax

rotation was used because it controlled for multicollinearity of the factors (Hair et al., 1998). The authors recommend the following:

To maximize prediction from a given number of independent variables, the researcher should look for independent variables that have low multicollinearity with the other independent variables but also have high correlations with the dependent variable. (pp. 157).

Trial runs of the factor analysis with items reverse coded were run against items that were all coded similarly. The two factor analyses yielded the same factors, with the only difference being negative values in the alpha coefficients.

Five variables loaded at Eigenvalues greater than an absolute value of 1. Factor analysis was done in two ways, 1) instructing SPSS to extract five factors, and 2) instructing SPSS to extract only those factors that loaded an Eigenvalue of 1. Both factor analyses yielded the exact same factor components. The components of these factors were identified and new variables were created accordingly. Scores for each participant were then obtained on each of the new factors. This yielded a total score on each of the new factors, and these scores became the independent variables that were used to test for hypothesis 2.

Research Question B

What relationships exist between coping response factors and caregiver burden in female caregivers for a family member that is living with HIV/AIDS in Kenya?

Hypothesis 1: Coping factors derived from the factor analysis of the Brief Coping will be significant predictors of caregiver burden among female caregivers for a family member that is living with HIV/AIDS in Kenya.

We failed to reject hypothesis 1 because the factor model yielded five significant factors that loaded at an Eigenvalue of 1. Additionally, a factor analysis instructing SPSS to extract only five factors extracted the very same factors that loaded at an Eigenvalue of 1. Consequently, the second hypothesis that was tested stated that coping factors derived from the factor analysis (Social support, Hope, Acceptance, Planning and Disposition) would be significant predictors of caregiver burden among female caregivers for a family member that was living with HIV/AIDS in Kenya.

Regression analyses were preceded by scatter plots for each variable to determine whether these variables were linearly related to overall caregiver burden. Regression analyses were then conducted using SPSS to investigate the relationships between each coping factor and caregiver burden among female caregivers for a family member that was living with HIV/AIDS in Kenya.

Post Analysis procedures

In order to further investigate the relationship between caregiver burden and caregiver characteristics, post hoc analysis of the data were conducted. The researcher sought to investigate the relationship between caregiver demographic variables and caregiver burden, as well as the relationship between certain care recipient characteristics and caregiver burden. Demographic variables were grouped into categories and these categories were further dummy coded for regression analysis. The results are presented in chapter 4.

CHAPTER 4

RESULTS

This study investigated caregiver burden and coping responses among female caregivers for a family member living with HIV/AIDS in Kenya. The study identified significant coping response factors in female caregivers for a family member that is living with HIV/AIDS in Kenya. The study also examined the relationships that existed among coping response factors and caregiver burden in female caregivers for a family member that is living with HIV/AIDS in Kenya.

To investigate coping factors among female caregivers for a family member that is living with HIV/AIDS in Kenya, a principal component factor analysis with varimax rotation was conducted on the Brief Cope. Five coping factors were extracted from this analysis. Regression analyses were conducted for each of these factors to investigate how they related to caregiver burden. Post hoc analyses also were conducted to investigate other relationships within the data, specifically the relationships between caregiver demographic variables and caregiver burden, and the relationship between care recipient characteristics and caregiver burden.

The sample consisted of 116 females that were the primary caregiver for a family member that was living with HIV/AIDS in Kenya. Participants were distributed as follows: 66 participants from Nairobi Province, making up 56.8% of the total participants, 33 participants from Central Province, making up 28.4% of the participants, and 17 participants from Rift Valley Province, representing 14.7% of the total participants. The participants in this study ranged in age from 14 to 80 years old. Details of the demographic variables are contained in Tables 3.1 and 3.2.

Variables of Interest

The goal of the first research question and hypothesis was to identify significant coping response factors in female caregivers for a family member that is living with HIV/AIDS in Kenya. This was done by means of a principle components factor analysis with varimax rotation. The factor analysis produced five significant coping factors that loaded at an Eigenvalue of 1. Sample means for the five factors and the 14 scales that make up the Brief Cope were obtained. The highest possible score for the 14 scales is 8. The highest possible score on each of the five factors (Social Support, Hope, Acceptance, Planning, and Disposition) is 16. These are presented in Table 4.1.

Table 4.1

Means and standard deviations among variables of interest.

Variables	Mean	SD
BRIEF COPE SCALES		
Self-Distraction	5.17	1.960
Active Coping	7.09	1.312
Emotional Support	6.25	1.955
Instrumental Support	6.33	1.904
Venting	4.13	1.931
Positive Reframing	6.44	1.434
Planning	7.06	1.286
Humor	2.51	1.195
Acceptance	7.19	1.349
Religion	7.51	1.063
Self Blame	6.32	2.088
Substance Use	7.72	.974
Denial	7.26	1.457
Behavioral Disengagement	6.66	1.721
FIVE FACTORS EXTRACTED		
SOCIAL SUPPORT	12.57	3.505
HOPE	12.98	3.182
ACCEPTANCE	14.98	1.943
PLANNING	11.19	2.547
DISPOSITION	2.51	1.195

A bivariate correlation was conducted to describe the existence of any relationships between two sets of variables: (Set 1) the 14 scales of the Brief Cope (Self-Distraction, Active coping, Denial, Substance use, Use of emotional support, Use of instrumental support, Behavioral disengagement, Venting, Positive reframing, Planning, Humor, Acceptance, Religion, and Self-blame) and (Set 2) the five factors that were produced by the factor analysis (Social Support, Hope, Acceptance, Planning, and Disposition). The correlation matrix among the variables of interest in the analysis of the first research question/hypothesis is presented in Figure 4.1.

There was apparent multicollinearity with the large correlations between Support and Instrumental Support (.903) and Emotional Support (.909). Tabachnik & Fidell (1995) suggested that bivariate correlations above .90 were needed for the effects of multicollinearity to become apparent. It was noted however that these two scales were the contributing scales to the Social Support factor on the factor analysis and therefore, this multicollinearity was expected.

Figure 4.1

Correlation Matrix: Brief Cope scales and Coping Factors

	SUP	HOPE	ACCE	PLAN	DISP	SD	AC	Deny	SU	ES	IS	BD	SB	Vent	PR	Plan	HMR	Rel	acpt	
SUP	1	-.145	-.013	.200*	.032	.252**	.147	-.071	.080	.909**	.903**	-.018	-.205*	.243**	-.070	.031	.032	.160	.025	
HOPE		1	.259**	-.126	-.106	-.292**	.007	.259**	.128	-.056	-.209*	.797**	.867**	-.141	.263**	-.038	-.106	-.013	.097	
ACCE			1	-.132	-.141	-.132	.325**	.874**	.687**	-.058	.038	.188*	.239*	-.207*	.249**	.050	-.141	.095	.154	
PLAN				1	.074	.234*	.176	-.227*	.078	.110	.254**	-.023	-.173	.870**	.186*	.674**	.074	.151	.130	
DISP					1	.226*	.036	-.135	-.079	.002	.056	-.004	-.158	-.010	-.308**	.162	1.00**	-.133	.042	
SD						1	.161	-.238*	.093	.206*	.251**	-.261**	-.230*	.189*	-.154	.180	.226*	.174	.012	
AC							1	.255**	.266**	.092	.169	.076	-.052	.095	.334**	.205*	.036	.091	.019	
Deny								1	.247**	-.099	-.027	.174	.252**	-.239*	.176	-.092	-.135	-.016	.159	
SU									1	.032	.116	.115	.100	-.055	.233*	.237*	-.079	.214*	.068	
ES										1	.642**	.006	-.090	.156	-.089	-.016	.002	.074	.002	
IS											1	-.040	-.285**	.286**	-.038	.074	.056	.219*	.045	
BD												1	.389**	-.095	.307**	.097	-.004	.072	.060	
SB													1	-.137	.148	-.138	-.158	-.079	.098	
Vent														1	.011	.223*	-.010	.027	.081	
PR															1	.351**	-.308**	.172	.117	
Plan																1	.162	.259**	.137	
HMR																	1	-.133	.042	
Rel																		1	.048	
Acpt																				1

*Correlation is significant at the 0.05 level (2-tailed). ** Correlation is significant at the 0.01 level (2-tailed).

The second research question sought to predict caregiver burden based on the coping factors identified from the factor analysis. A regression analysis was conducted to investigate what relationship existed among the five factors and the caregiver burden. The correlation matrix among the variables of interest for the analysis investigating the second research question and hypothesis is presented in Table 4.2. No problems with multicollinearity are observed in this matrix.

Table 4.2

Correlation Matrix: Caregiver Burden and Coping Factors

	Support	Hope	Accept	Plan	Disp	CGB
Support	1	-.145	-.013	.200*	.032	.147
Hope		1	.259	-.126	-.106	-.563
Accept			1	-.132	-.141	-.182
Plan				1	.074	.224*
Disp					1	.031
CGB						1

*p<.05

Testing for Research Question A

The hypothesis that was used to test the first research question stated that a factor analysis of the Brief Cope (Carver, 1997) would produce five significant coping factors for female caregivers of a family member that is living with HIV/AIDS in Kenya. A principal component factor analysis with varimax rotation on the Brief Cope was used to test this hypothesis. The factor analysis extracted five factors that all loaded at an acceptable Eigenvalue of 1 and together, accounting for 60% of the total variance. A review of the initial factor loadings suggests that a proper solution was attainable through principal components analysis, as it was capable of converging in 9 iterations. The composition matrix for the five factors is presented in Figure 4.2.

Figure 4.2

Factor Analysis Components

	Component				
	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
Self distraction		.503			
Active coping			.697		
Denial			-.613		
Substance use			-.704		
Emotional support	.886				
Instrumental support	.872				
Behavioral disengagement		.751			
Venting				.560	
Positive reframing					
Planning				.789	
Humor					.881
Acceptance					
Religion					
Self blame		.701			

Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalization. Rotation converged in 9 iterations.

Factor 1: This factor was most highly correlated with emotional support (Cronbach's alpha coefficient of .886) and instrumental support (Cronbach's alpha coefficient of .872). This factor was labeled *Social Support* and accounted for 13% of the total variance observed on the rotation sum of squared loadings.

Factor 2: The components for factor 2 were behavioral disengagement with a Cronbach's alpha coefficient of .751 and self-blame with a Cronbach's alpha coefficient of .701. This factor was labeled *Hope* and it explained 12.7% of the total variance on the rotation sum of squared loadings.

Factor 3: Factor 3 was composed of substance use and active coping. This component explained 12.7% of the total variance. Cronbach's alpha coefficients were -.704 and .697 respectively. The factor was labeled *Acceptance*.

Factor 4: This factor was representative of planning and venting with Cronbach's alpha coefficients of .789 and .560 respectively. They accounted for another 12.1% of the total variance. This factor was labeled *Planning*.

Factor 5: This had a unique loading, with only the humor scale that had a Cronbach's alpha coefficient of .881 and it was named *Disposition*. Factor 1 and 2 had the strongest loadings and together accounted for 25% of the total variance. The third and fourth factors explained about 24% of the total variance. Although factor 5 had a unique loading, it was retained because of the high variance for which it accounted (9.4%). This factor also had a high Cronbach's alpha that made it reliable enough to be considered as a factor.

The five factors together explained more than 60% of the total variability in the original 14 scales (variables). Consequently, the complexity of the data could be reduced to these five factors with only a 40% loss of information. These five factors (Social Support, Hope, Acceptance, Planning, and Disposition) yielded by the factor analysis became the independent variables against which caregiver burden was measured to test hypothesis 2.

Testing for Research Question B

The second hypothesis stated that coping factors derived from a factor analysis of the Brief Cope would be significant predictors of caregiver burden among female caregivers for a family member that is living with HIV/AIDS in Kenya.

The variables in the testing of the second hypothesis were caregiver burden scores and coping factors obtained in the factor analysis. Caregiver burden scores were obtained by totaling participant's responses on the 22 items on the Zarit Caregiver Burden Inventory. The mean for the total caregiver burden score was 37.18 (SD=17.5). According to the cutoffs proposed by Zarit and Zarit (1987), this is indicative of mild to moderate burden. Twenty two participants (19%) were experiencing little to mild caregiver burden. There were forty nine participants (42.2%) who reported mild to moderate caregiver burden, thirty one (26.7%) who reported moderate to severe burden, and thirteen (11.2%) who reported experiencing severe caregiver burden.

A multiple regression analysis was performed to investigate relationships that exist between the dependent variable (caregiver burden) also known as the criterion variable and the independent variables (Social Support, Hope, Acceptance, Planning, and Disposition), also known as predictor variables.

Preliminary Analysis

A preliminary analysis procedure using case wise diagnostics was initiated in order to scrutinize the data for normal distribution, outliers, missing data, and linearity. In order to ensure that the data was normally distributed, a histogram was obtained and this indicated that the data was normally distributed. A residual analysis was applied to detect any outliers or extreme values that might adversely affect the final outcome. The residual values were reported for each case on caregiver burden. Two cases were excluded, one for missing data (number 6), and one that was an outlier (number 115) with a standard residual of 3.251.

Summary of results for the multiple regression.

The multiple regression analysis indicated that the overall coping factors model (Social Support, Acceptance, Planning, and Disposition) was a statistically significant predictor of caregiver burden ($F=11.336$, $df =5$, 1108 , $p<.01$). This model explained 31.4% of the total variance in caregiver burden scores. The regression coefficients indicate that Hope was the only coping factor that had a unique contribution to the model at the .001 level ($t= -6.531$, $p<.01$). The effect of Social Support ($t=.566$, $p>.05$), Acceptance ($t=-.363$, $p>.05$), Planning ($t=1.828$, $p>.05$), and Disposition ($t=-.366$, $p>.05$) are not significant.

The multiple regression equation for caregiver burden is:

$$\text{CAREGIVER BURDEN} = 66.635 + .228(\text{SOCIAL SUPPORT}) - 2.961(\text{HOPE}) - .267(\text{ACCEPTANCE}) + 1.013(\text{PLANNING}) - .433(\text{DISPOSITION}).$$

Post Hoc Analyses

In order to further investigate the relationship between caregiver burden and caregiver demographic variables as well as care recipient characteristics, the researcher conducted further analyses of the data. Demographic variables were grouped into categories and these categories were dummy coded for regression analysis. Age of caregiver and age of care recipient were both placed into 7 categories with 10 year intervals. The number of years in school was placed into 4 categories that reflect no formal education, primary school, high school, and college. The other variables that were turned into categorical data were monthly household income, number of persons living in household, duration of care in months, number of persons being cared for, HIV status of the caregiver, and their relationship to the care recipient. In coding the relationship to the

care recipient, male and female care recipients were coded alike when the care recipient was a sibling, a parent, or a relative/friend/other.

Multiple regression analyses explored the relationship between each of these variables and caregiver burden. The findings of the regression analyses are presented in Table 4.3.

Table 4.3

Caregiver demographic variables and caregiver burden regression analyses

Variable	F Change	Sig.	Adjusted R Square
Age of care giver	*2.825	.019	.074
Number of years in school	*2.928	.037	.048
Monthly hshld income	1.412	.235	.014
Number of persons in hshld	.105	.747	-.008
Number of care recipients	.939	.444	-.002
HIV status of caregiver	.582	.560	-.007
Duration of care	.825	.534	-.008
Relationship to recipient	.616	.606	-.010

*p<.05

The multiple regression analysis indicated that the age of the caregiver was a predictor of caregiver burden ($F_{5, 110} = 2.825, p = .02$). As age increased, there was a significant decrease in caregiver burden. Age of the caregiver explained about 7% of the total variance in total caregiver burden scores. Education level also was a predictor of

burden ($F_{5,110} = 2.928, p = .04$). Caregiver burden decreased significantly with an increase in education level. The number of years in school explained 4.8% of the variance in caregiver burden scores. None of the other demographic variables were found to be significant predictors of caregiver burden among this population. These findings are discussed in chapter 5.

The relationship between care recipient characteristics and caregiver burden was also investigated with multiple regression analyses. The age of the caregiver and the functional level of the care recipient were the independent variables. The functionality of the care recipient was obtained by summing the responses on the five items on the demographic questionnaire that sought to obtain information on activities of daily living. The results are presented in Table 4.4.

Table 4.4

Care recipient characteristics and caregiver burden regression analyses

Variable	F Change	Sig.	Adjusted R Square
Age of care recipient	*.771	.573	-.010
Activities of daily living	*3.580	.061	.022

* $p < .05$

The regression analysis found that the age of care recipient was not a significant predictor of caregiver burden ($F_{5,110} = .771, p > .05$). The summed score on activities of daily living was also not a statistically significant predictor of caregiver burden ($F_{5,110} = 3.580, p < .05$). These findings are also discussed in chapter 5. The conclusion of the post hoc regression analyses was that caregiver burden among the population of this study can be predicted by age of the care giver and their level of education.

In summary, the principle components factor analysis of the Brief Cope yielded five coping factors: Social support, Hope, Acceptance, Planning, and Disposition. The regression analysis that was conducted to investigate the relationships between these five coping factors and caregiver burden indicated a significant inverse relationship between Hope and caregiver burden. The post-hoc analyses investigating the relationship between various caregiver and care recipient characteristics indicated a significant relationship between the caregiver's age and caregiver burden, and education level and caregiver burden.

CHAPTER 5

DISCUSSION

This study examined coping factors and caregiver burden among female caregivers of a family member living with HIV/AIDS in Kenya. Coping factors were derived from a principal components factor analysis of the fourteen scales on the Brief Cope (Carver, 1997). Caregiver burden was measured using the Zarit Caregiver Burden Inventory. Multiple regression analysis investigated the relationships among caregiver burden and coping factors. Post-hoc regression analyses further investigated the relationship between caregiver burden and caregiver demographic characteristics, as well as care recipient characteristics.

This study identified coping factors that female caregivers in Kenya utilize to mediate the effects of caregiving. These factors were identified and labeled as Social Support, Hope, Acceptance, Planning, and Disposition. The coping factors produced by the factor analysis are consistent with what has been identified as coping factors or responses in previous studies of coping among caregivers. The importance of social support (McCausaland & Pakenham, 2003; Parks & Pilisuk, 1991), hope (Akinsola, 2001; Folkman, 1997), acceptance (Brouwer et al., 2000; Mellins & Ehrhardt, 1994), planning (Stewart, Hart & Manning, 1995), and disposition (Folkman, 1997; Hooker et al., 1992; Scheier et al., 1989) as coping strategies has been documented.

There were only two other studies conducted examining coping factors in African populations (Mushonga, 2001; Olley et al., 2005). Mushonga (2001) studied 151 caregivers of HIV/AIDS patients in Zimbabwe and found that social support, stigma, and the patients' functional level on instrumental activities of daily living were significant

predictors of caregiver burden. This author also found that affective coping was significantly related to caregiver burden as well. Olley et al. (2005) investigated coping and post traumatic stress disorder among patients recently diagnosed with HIV in South Africa and found that active planning, venting, denial, social support and substance use were significant coping factors with that population.

When the relationship between the five coping factors and caregiver burden was examined, Hope emerged as the one significant predictor of caregiver burden ($t = -6.531$, $p < .001$). The negative coefficient indicates a reverse relationship between the variables of hope and caregiver burden. In this study, Hope represented two scales on the Brief Cope, namely, behavioral disengagement, and self-blame. The items that contributed to these scales were as follows: Behavioral disengagement (Item 6: I've been giving up trying to deal with it, and Item 16: I've been giving up the attempt to cope) and Self-blame (Item 13: I've been criticizing myself, and Item 26: I've been blaming myself for things that happened). Both of these scales were reverse coded so that participants who did not engage in the behaviors implied by the items were rated higher. This study found that participants who reported not 'giving up dealing' or not 'giving up coping' with their situation perceived reduced caregiver burden than those who were giving up. Participants who did not blame or criticize themselves also had lower caregiver burden scores than those who reported blaming themselves or criticizing themselves.

A preliminary comparison of the factors identified in this study and those that have been identified in studies with American caregivers reveals some areas of commonality as well as some differences. One striking difference pertains to the use of religion as a coping response. In American studies, religiosity has been identified as one

of the most important coping responses among caregivers (Picot, 1995; Tolliver, 2001). It was expected that religiosity would also emerge as a significant coping factor among the population studies. However, the present study did not identify religion as a significant coping factor even though over 73% of the respondents reported praying or meditating more. The researcher hypothesizes that the reduced variance in responses to this item might account for the non-identification of religion as a way of coping.

Previous research found that seeking emotional support or instrumental support were important coping factors among caregivers (Parks & Pilisuk, 1991; Pratt et al., 1985). As expected, social support was an important coping factor with the population of the present study. However, this study found that while social support was a significant coping factor, it did not contribute significantly to the easing of caregiver burden. The participants in this study rated emotional support highly with a mean of 6.25 out of a possible eight points for the emotional support scale, and a mean of 6.33 for instrumental support out of a possible eight points. This would indicate that seeking and obtaining emotional and instrumental support is an important coping response for this population. As caregivers struggle to provide the care recipient with medication, dietary requirements as a result of illness, and at the same time meet their own needs as well as those of other family members, instrumental support is vital for survival (Olenja, 1999).

An unexpected finding was the lack of a significant relationship between Social Support as a coping factor and caregiver burden. Prior research found social support to be an important mitigating factor for caregiver burden (McCausaland & Pakenham, 2003; Rose & Clark-Alexander, 1999). The results of the present study differed from this finding. It is likely that with the restructuring of the extended family in Kenya (Olenja,

1999) caregivers may not be able to obtain the support that they need. The factor that was labeled Social Support included both emotional and instrumental support. It is estimated that instrumental support may be greatly hampered by limitations such as meager financial means etc.

The study also measured caregiver burden as experienced by the female caregivers in Kenya. According to the cutoffs proposed by Zarit and Zarit (1987), the majority of caregivers in the study experienced mild to moderate caregiver burden. A total of 49 (42.2%) of the caregivers reported experiencing mild to moderate burden. Only 13 (11.2%) caregivers reported experiencing severe caregiver burden.

These statistics should be interpreted with caution for several reasons. First, women in Africa as in most of the world are socialized to be carers and nurturers (Mushonga, 2001; Evans, 2005; Moore & Henry, 2005). The general perception of women as 'tower(s) of strength (Linsk & Poindexter, 2000) leaves no room for their protests or requests for help and the depth of their burden may go unnoticed until it is too late. Women as well are socialized to accept the responsibilities of caring as their lot in life (D'Cruz, 2004). As a result, it is possible that the degree of perceived burden is underreported because female caregivers consider the tasks of caregiving as their obligation. Previous studies have indicated gender differences in caregiver burden (Onishi et al., 2005) with women performing more tasks than men who take on the same role (Gallicchio et al., 2002).

The present study utilized a good sample size (n=116). Although the strength of the study may be reduced by the homogeneity of the sample, it is important to keep in mind that the population in this study reflects the prevalence patterns of HIV/AIDS in

Kenya. Most of the participants in this study were recruited from Korogocho, Mathare and Soweto. These are all areas that share low economic status and a generalized lack of resources. They are also the parts of Nairobi with the most severe infection rates (KENWA, 2004). The findings of this study therefore contribute significantly to a better understanding of caregiver burden as experienced by female caregivers in Kenya.

Limitations in the study

The most obvious threat to the internal validity of this study pertains to instrumentation. A review of the instruments available to measure the constructs of interest to this study revealed that none of these instruments had been normed for use with African populations. The closest use of the Brief Coping with this population was a study of post traumatic stress disorder with newly diagnosed HIV patients in South Africa (Olley et al., 2004). Although the Brief Coping has been used with several populations, its most prevalent use has been with White North American populations. Some studies have utilized translations of the Brief Coping in other languages – Spanish (Perczek, 2000) and French (Muller & Spitz, 2003) - and with other populations but such use remains limited.

Caregiver burden was measured with the Zarit Caregiver Burden Inventory. This instrument was normed with mostly white caregivers of persons with dementia. There exist several translations of this instrument – French (Hebert et al., 1993), Japanese (Onishi et al., 2005; Takahashi, et al., 2005), and Spanish (Gutierrez-Maldonado et al., 2005). However, a review of the literature found no use of this instrument with any African populations. The lack of previous research among African populations with these instruments has implications for the validity of the instruments. It is questionable whether

the instruments are the best tools to measure the constructs under study with the current population.

A second threat to internal validity was the effects of translation. The researcher made every effort to ensure that the content of the items was retained and transferred in the process of translation. Translation involved not only the linguistic translation of words from English to Swahili or Kikuyu, but also the transfer of ideas and concepts in a manner that ensured they remained culturally relevant. This was a complicated process, especially because of the prevalence of different dialects in the same language. This was the case in Swahili translations because people in urban areas speak an informal version of Swahili called *Sheng* and the vocabulary and meanings assigned to phrases may vary from one area to another.

Threats to external validity in this study involve sampling procedures. A convenience sampling procedure was utilized, with information going out to recruit any person that was deemed to meet the criteria for the study. The use of AIDS agencies as recruiting centers for the study may also preclude a bias in that these are individuals who may already have access to a support network through their affiliation with the AIDS agency.

The majority of the participants in this study were recruited from Mathare, Soweto and Korogocho. These are all outskirts of Nairobi that are characterized by low economic status households. Most houses are shanties made of corrugated iron sheets. There are no paved roads and the sewer systems are in disrepair. Majority of the families who live in these areas live well below the poverty line as reflected in the reported monthly household income (range 300 Kenya Shillings -20,000 Kenya Shillings). More

than eighty seven percent (87.9%) of the participants in this study had a total household income that was less than 5000 Kenya shillings a month. The socioeconomic homogeneity of the population reduces the generalizability of these findings. Future research with female caregivers in Kenya would benefit from obtaining a more varied sample. A more accurate picture would be obtained from a sampling procedure that drew participants from varied socioeconomic backgrounds.

Implications for practice

This study has important implications for mental health professionals in Kenya. First of all, it is important to note that counseling is a young profession in Kenya. Current initiatives are geared towards persons who are infected with HIV/AIDS. As the numbers of persons with AIDS continue to grow, the burden of care continues to shift to the families of the infected persons (Olenja, 1999). In light of this, mental health professionals need to direct more attention towards family caregivers. Understanding the challenges that family caregivers are faced with in their caregiving experience will be an important first step in enhancing caregiver wellbeing, and in turn, impacting the patients' health in a positive way. Cumming et al., (2002) discuss the relationship between caregiver wellbeing and the health of the care recipient. As mental health strategies are designed for caregivers, it is important to keep in mind the coping factors that mitigate caregiver burden and to design interventions that facilitate these coping factors.

This study demonstrated the significance of fostering hope among caregivers. Counseling efforts should then be geared towards fostering hope in caregivers. It is important to note that one of the contributing scales to the Hope factor is self-blame. In

light of the social stigma that surrounds HIV/AIDS in Kenya, it is particularly important that caregivers do not blame or criticize themselves and their patients.

The morale and outlook of caregivers are important factors in the provision of quality care for the AIDS patient (Mushonga, 2001; UNAIDS, 2000). In the face of such adversity as the current HIV statistics indicate, it is easy for both caregivers and their patients to give up. In Africa particularly, the limited understanding of HIV/AIDS (Nzioka, 2000; Olenja, 1999) leads to a social stigmatization of the disease. The lack of education and the limited access to medical facilities in Africa (Freeman, 2000) has often led to the view of HIV as a death sentence. Individuals who are infected with HIV are inclined to give up hope because there is no known cure for the HIV virus and they have no access to medicine that would enhance their quality of life. Efforts to make antiretroviral drugs available to Kenyans living with HIV/AIDS could have a significant effect not only by enhancing immune levels, but most importantly, by fostering hope among HIV/AIDS patients and their caregivers.

Caregivers could also benefit from practical support and emotional support through community resources. Possible interventions may include peer support groups where older caregivers who report lower caregiver burden are paired with younger caregivers. This kind of support group could serve to increase hope among those caregivers who were experiencing heightened caregiver burden, and in turn, positively impact their wellbeing.

Mental health workers can help caregivers anticipate and prevent stressful situations in caregiving by educating them and equipping them with skills needed for the tasks they perform. It is important to validate caregivers' experiences and assist them in

finding ways to sustain hope. This will positively impact the caregivers as well as the persons that they provide care for.

Implications for research

The present study was an initial exploration into the experiences of caregivers for a family member living with AIDS in Kenya. The findings of this study can serve as a guide for future research in this area. One important accomplishment of this study is the validation of the Brief Cope and the Zarit Caregiver Burden Inventory with Kenyan caregivers. Davis (1998) called for more studies that validated instruments in distinct caregiver groups in order to assist in the provision of optimum functioning and health. Future research using these instruments would help to improve the metric properties of the instruments.

It would be beneficial for this study to be replicated with a larger sample size of caregivers. It would also be beneficial to have a sample that was more representative of the different socioeconomic groups in Kenya. Improved heterogeneity of the sample would have the benefit of enhancing the generalizability of the findings beyond the present sample. A research study with a control group investigating the efficacy of interventions that are designed to foster hope or provide support may also be helpful in identifying interventions that are effective for caregivers in Kenya.

The results also demonstrate a need for further research to examine the role of gender socialization in reporting caregiver burden. Previous research found that women caregivers were less likely to report caregiver burden than men caregivers (Songwathana, 2001). Possibilities for future research may include replicating this study with male caregivers to examine differences between male and female caregivers in Kenya.

Conclusion

This study investigated caregiver burden and coping responses among female caregivers for a family member living with HIV/AIDS in Kenya. The study identified significant coping response factors in female caregivers for a family member that is living with HIV/AIDS in Kenya. The study also examined the relationships that existed among coping response factors and caregiver burden in female caregivers for a family member that is living with HIV/AIDS in Kenya.

In summary, the principle components factor analysis of the Brief Cope yielded five coping factors: Social support, Hope, Acceptance, Planning, and Disposition. The regression analysis that was conducted to investigate the relationships between these five coping factors and caregiver burden indicated a significant inverse relationship between Hope and caregiver burden. The post-hoc analyses investigating the relationship between various caregiver and care recipient characteristics indicated a significant relationship between the caregiver's age and caregiver burden, and education level and caregiver burden. The post hoc regression analyses indicated that caregiver burden among the population of this study can be predicted by age of the care giver and their level of education.

A significant relationship was found between Hope and caregiver burden. Participants who had higher scores in Hope experienced reduced caregiver burden. Education level and age of the caregiver were also found to be significantly related to caregiver burden. Caregiver burden decreased as age of caregivers increased. Caregiver burden also decreased as the education level increased. These findings have far reaching

implications for the HIV/AIDS education and counseling on all levels ranging from governmental, non-governmental and community levels.

This study has important implications for the practice of mental health counseling in Kenya. It provides information about current caregiving coping factors and provides a framework for intervention design and implementation. The study also raises some pertinent questions to be addressed in future research with caregivers in Kenya and in Africa. It is expected that this study will provide useful information to organizations that work with the population affected by HIV/AIDS in Kenya. The findings will be presented at various conferences, most notably, conferences for counselors in Kenya. It is the goal of the researcher to share information with AIDS organizations in Kenya such as the Kenya Network of Women with AIDS (KENWA), and Women Fighting AIDS in Kenya (WOFAK). Additionally, the Kenya ministry of Health can use the findings of this study to inform the services that are currently provided at Voluntary and Counseling Centers (VCT's) around the country.

The present study had limitations pertaining to instrumentation as well as homogeneity of the sample. In spite of these limitations, the study provides some significant information that is crucial in beginning to understand the experiences of caregivers in Kenya. The study is also an important first step towards the validation of instruments to measure caregiver burden as well as coping responses among caregivers in Kenya. It is hoped that this project will make a positive contribution to research on the experiences of caregivers in Kenya, and indeed, in Africa.

APPENDIX A: INSTITUTIONAL REVIEW BOARD APPROVAL

IRB Approval



Office of Research & Commercialization

September 1, 2005

Ms. V. Muthoni Kimemia
5144 Conroy Road, Apt. 1037
Orlando, Fl 32811

Dear Ms. Kimemia:

With reference to your protocol #05-2838 entitled, "**Caregiver Burden and Coping Responses for Females who are the Primary Caregiver for a Family Member Living with HIV/AIDS in Kenya**," I am enclosing for your records the approved, expedited document of the UCFIRB Form you had submitted to our office. **This study was approved by the Chairman on 8/30/05. The expiration date for this study will be 8/29/06.** Should there be a need to extend this study, a Continuing Review form must be submitted to the IRB Office for review by the Chairman or full IRB at least one month prior to the expiration date. This is the responsibility of the investigator. **Please notify the IRB when you have completed this study.**

Please be advised that this approval is given for one year. Should there be any addendums or administrative changes to the already approved protocol, they must also be submitted to the Board through use of the Addendum/Modification Request form. Changes should not be initiated until written IRB approval is received. Adverse events should be reported to the IRB as they occur.

Should you have any questions, please do not hesitate to call me at 407-823-2901.

Please accept our best wishes for the success of your endeavors.

Cordially,

A handwritten signature in cursive script that reads "Barbara Ward".

Barbara Ward, CIM
UCF IRB Coordinator
(FWA00000351, IRB00001138)

Copy: IRB file
Dr. Andrew Daire - Child, Family and Community Sciences

BW:cc

APPENDIX B: PARTICIPANT INVITATIONAL LETTER

Invitation to Interview

Researcher Information

Name: V. Muthoni Kimemia
Address: College of Education
University of Central Florida
P.O. Box 161250
Orlando, FL 32816
Phone: (407) 782 - 4754

Supervisor Information

Dr. Andrew P. Daire
College of Education
University of Central Florida
P.O. Box 161250
Orlando, FL 32816
(407) 823 - 0385

I am a Ph. D candidate in the Counselor Education program at the University of Central Florida and being supervised by Dr. Andrew P. Daire. As part of my coursework, I am conducting a study, the purpose of which is to learn about the experiences of caregivers for family members living with HIV/AIDS. I am inviting you to participate in this study because you have been identified as a person caring for a family member with HIV/AIDS. If you agree to participate in this study, you will be asked to provide contact information where I can reach you to make an appointment for an interview with you. You may also call me to make arrangements for an interview appointment. **My phone number is (0723) 709 088.**

The interview will consist of three questionnaires, a caregiver demographic questionnaire, a coping responses survey and a caregiver burden survey. The interview is expected to last one hour and will be audio-recorded. The recordings are to assist me in my note taking only and will not be used for any other purposes. For the duration of the study, all recordings will be stored at a safe location and will be destroyed at the conclusion of this study. You will not have to answer any questions that you do not wish to answer. Your identity will be kept confidential and will not be revealed in the final manuscript.

If you agree to participate in this study, there is a minimal potential for risk with emotional discomfort when thinking about your care giving role. However, you can discontinue the interview at any time without consequence. You will receive compensation for your time in the amount of Kenya Shillings 150.00. You are free to withdraw your consent to participate and may discontinue participation in the interview at any time. All consent forms and instruments completed will be kept in a locked strong box until return to the University of Central Florida where they will be kept in a locked filing cabinet.

You are encouraged to ask any questions at any time about the nature of this study and the methods that I am using. Research at the University of Central Florida involving human participants is carried out under the oversight of the Institutional Review Board. Questions or concerns about research participants' rights may be directed to the UCFIRB office, University of Central Florida Office of Research, Orlando Tech Center, 12443 Research Parkway, Suite 207, Orlando, FL 32826. The phone number is (407) 823-2901.

UCFIRB
APPROVED *SFD*
DATE *8/30/2005*

I guarantee that the following conditions will be met:

- 1) Your full names will not be used at any point of data analysis, data storage, or in the written report. All names involved in your case will be given pseudonyms/numbers that will be used in all verbal or written records and reports. At the conclusion of the study, all digital audio recordings will be deleted.
- 2) If you grant permission for audio recording, the information collected will not be used for any purpose other than for research under the Principal Investigator, and will not be played for any reason other than for analyzing this research. You may request at any time during the interview that the research stop recording.
- 3) Your participation in this research is voluntary; you have the right to withdraw at any point of the study, for any reason, and without any prejudice, and the information collected and records and reports written will be turned over to you.

Thank you very much for your contribution to this study.

Sincerely,

Muthoni Kimemia

Please sign below to indicate your willingness to participate in this study.

I have read and understood the procedure described above. I am interested in participating in this study and give permission for the researcher to contact me. My contact information is provided here below.

Phone number: _____

Address: _____

Signed: _____

You may also call Muthoni Kimemia on (0723) 709-088 to set up an appointment for an interview. Thank you very much.

UCF IRB
APPROVED *SFD*
DATE *8/20/2006*

APPENDIX C: PARTICIPANT CONSENT LETTER

Consent for Interview

Consent for Interview

Researcher Information

Name: V. Muthoni Kimemia
Address: College of Education, University of Central Florida
P.O. Box 161250 Orlando, FL 32816
Phone: (0723) 709 088

Thank you for agreeing to participate in this study. You will be asked a number of questions for a period of **one hour**. Your identity will not be disclosed and your responses will not be discussed with anyone. All publications from this study will use code names and will not reveal your identity. This interview will be tape-recorded. The recordings are to assist me in my note taking only and will not be used for any other purpose. **For the duration of the study, all recordings will be stored at a safe location and will be destroyed at the conclusion of this study.** You will not have to answer any questions that you do not wish to answer. Your identity will be kept confidential and will not be revealed in the final manuscript.

Your participation in this research is voluntary. **If you experience any emotional discomfort, you are free to stop the interview at any time.** You will not have to answer any question that you do not wish to answer. You will receive compensation for your time in the amount of Kenya Shillings 150.00. You may request to stop the interview or the recording at any time if you feel uncomfortable and still receive the Kenya Shillings 150.00. Please feel free to ask any questions at any time about the study and the methods that I am using. **I will be available to answer any questions that you may have. My phone number is (0723) 709 088 and you can call me at any time.**

To make sure that you understand the procedures of this study, I am asking _____ to also review this consent form with you and answer any questions that you may have. You can stop me at any time during the interview to ask questions of both myself and _____.

Research at the University of Central Florida is carried out under the oversight of the Institutional Review Board. Questions or concerns about research participants' rights may be directed to the UCFIRB office, University of Central Florida Office of Research, Orlando Tech Center, 12443 Research Parkway, Suite 207, Orlando, FL 32826. The phone number is (407) 823-2901.

Sincerely,

Muthoni Kimemia

_____ I have read and understood the procedure. / The procedures have been explained to me.

_____ I voluntarily agree to participate in the interview.

_____ I grant my permission for the interview to be audio-recorded.

UCF IRB

APPROVED SED

DATE 8/30/2005

Participant _____ Date _____

WITNESS

I have observed the oral presentation of the informed consent information to the participant. The process included all the required elements and in my judgment, the participant seemed capable of making an informed decision. The participant was not coerced in any way and was given an opportunity to ask me and/or the researcher any questions that they have.

Signature _____ Date _____

APPENDIX D: INSTRUMENTATION

Caregiver Demographic Questionnaire

by Muthoni Kimemia

1. Your Gender

Female

Male

2. Your age (CG) _____

3. Age of Care Recipient _____

4. What is your estimated monthly household income? _____

5. Number of years in school _____

6. How many other people live in your household? _____

7. How long have you been providing care for *?** _____ months

8. How many people are you currently providing care for? _____

9. Your HIV status

Positive

Negative

Don't know

10. The care recipient is my:

Spouse/significant other

Parent

Son/Daughter

Sibling

Relative/ Friend/ Other

Please rate the care recipient's functioning in each area:

		1 Independent	2 Needs supervision	3 Needs assistance	4 Needs total help
11.	Walking				
12.	Bathing				
13.	Dressing				
14.	Getting in and out of bed				
15.	Toileting				

Thank you for completing this survey

ZARIT CAREGIVER BURDEN INTERVIEW

Instructions: Instructions for caregiver: The questions below reflect how persons sometimes feel when they are taking care of another person. After each statement, circle the word that best describes how often you feel that way. There are no right or wrong answers.

0 - Never

1 - Rarely

2 - Sometimes

3 - Quite Frequently

4 - Nearly always

1.	Do you feel that your relative asks for more help than he/she needs?					
2.	Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?					
3.	Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?					
4.	Do you feel embarrassed over your relative's behavior					
5.	Do you feel angry when you are around your relative?					
6.	Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?					
7.	Are you afraid what the future holds for your relative?					
8.	Do you feel your relative is dependent on you?					
9.	Do you feel strained when you are around your relative?					
10.	Do you feel your health has suffered because of your involvement with your relative?					
11.	Do you feel that you don't have as much privacy as you would like because of your relative?					
12.	Do you feel that your social life has suffered because you are caring for your relative?					

		0 - Never	1 - Rarely	2 - Sometimes	3 - Quite Frequently	4 - Nearly always
13.	Do you feel uncomfortable about having friends over because of your relative?					
14.	Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?					
15.	Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?					
16.	Do you feel that you will be unable to take care of your relative much longer?					
17.	Do you feel you have lost control of your life since your relative's illness?					
18.	Do you wish you could leave the care of your relative to someone else?					
19.	Do you feel uncertain about what to do about your relative?					
20.	Do you feel you should be doing more for your relative?					
21.	Do you feel you could do a better job in caring for your relative?					
22.	Overall, how burdened do you feel in caring for your relative?					

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Thank you for completing this survey

BRIEF COPE

BRIEF COPE		1- I haven't been doing this at all	2- I've been doing this a little bit	3- I've been doing this a medium amount	4- I've been doing this a lot
Instructions: After each statement, indicate the response that best describes your situation. There are no right answers.					
1.	I've been turning to work or other activities to take my mind off things.				
2.	I've been concentrating my efforts on doing something about the situation I am in.				
3.	I've been saying to myself "this isn't real."				
4.	I've been using alcohol or other drugs to make myself feel better.				
5.	I've been getting emotional support from others.				
6.	I've been giving up trying to deal with it.				
7.	I've been taking action to try make the situation better.				
8.	I've been refusing to believe that it has happened.				
9.	I've been saying things to let my unpleasant feelings escape.				
10.	I've been getting help and advice from other people.				
11.	I've been using alcohol or other drugs to help me get through it.				
12.	I've been trying to see it in a different light, to make it seem more positive.				
13.	I've been criticizing myself.				
14.	I've been trying to come up with a strategy about what to do.				
15.	I've been getting comfort and understanding from someone.				
16.	I've been giving up the attempt to cope.				

CONTINUE HERE

		I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
17.	I've been looking for something good in what is happening.				
18.	I've been making jokes about it.				
19.	I've been doing something to think about it less, such as going to movies, watching tv, reading, daydreaming, sleeping, or shopping.				
20.	I've been accepting the reality of the fact that it has happened.				
21.	I've been expressing my negative feelings.				
22.	I've been trying to find comfort in my religion or spiritual beliefs.				
23.	I've been trying to get advice or help from other people about what to do.				
24.	I've been learning to live with it.				
25.	I've been thinking hard about what steps to take.				
26.	I've been blaming myself for things that happened.				
27.	I've been praying or meditating				
28.	I've been making fun of the situation.				

Carver, C.S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of behavior Medicine*, 4, 92-100.

Thank you for completing this survey

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