HIDDEN VICTIMS OF HIV/AIDS: THE IMPACT OF CAREGIVING ON ELDERLY CAREGIVERS

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COMPULSORY DECLARATION

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

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Date: 05/05/2008

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ABSTRACT

Background and Objective: The HIV/AIDS pandemic in South Africa and the concomitant high mortality rate of the middle generation has resulted in an increased number of orphans and vulnerable children (OVCs). The responsibility of care for these children has fallen to the extended family, especially elderly females. This study aimed to explore the impact of caregiving on grandmothers caring for OVCs in two Western Cape townships, and to statistically determine predictors of caregiver burden.

Method: Participants (n = 57) were members of a community-based supportive organisation, were grandmother caregivers to at least one grandchild, and lived in a household that was impacted by HIV/AIDS. A quantitative questionnaire, consisting of socio-demographic questions, as well as open-ended questions on participants' experiences within the organisation and of caregiving, was individually administered in Xhosa. The Burden Interview (BI), a standardised scale, was used to measure the impact of caregiving on the grandmothers across five dimensions (health, finances, psychological well-being, social life, and relationships).

Results: Descriptive statistical analysis of the socio-demographic questionnaire showed that caregiving occurred in the context of poverty, HIV/AIDS, chronic illness, and multi-generational households. Thematic analysis of the open-ended questions revealed that participants benefited financially and emotionally and gained knowledge and skills through membership of the community organisation. However, caregiving was commonly described as emotionally and physically exhausting. This burden was exacerbated by the age and health status of both caregiver and care-recipient, and behavioural difficulties in the care-recipient. A stepwise multiple regression analysis yielded three factors as significant predictors of burden (R^2 = .41): the number of children for which the participant was the primary caregiver; the number of chronically ill people in the household; and the need for assistance with caregiving responsibilities. The latter finding probably implies that those who are the most stressed are most likely to require assistance with care.

Conclusion: The findings highlight the important contribution of the elderly in buffering the psychosocial impact of the HIV/AIDS pandemic, sometimes at the expense of their own well-being. Policy-makers should consider the unique challenges and contributions of the elderly in this regard.

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CHAPTER ONE: INTRODUCTION AND BACKGROUND

The current study aims to quantitatively assess the degree of burden experienced by grandmothers caring for their grandchildren in households that have been impacted by the HIV/AIDS epidemic. I further aim to ascertain, by means of quantitative statistical analysis, which (or which combination of) socio-demographic factors best predicts the level of burden that such grandmothers experience as a result of caregiving.

This research falls within the ambit of multiple fields of study, including caregiving, ageing, and the social impact of HIV/AIDS. For the purposes of brevity, I have, in this review, focussed on the literature most pertinent to my area of study, elderly caregivers. I have also attempted to focus on literature salient to the current South African context within which my study was conducted. I have in this regard considered primarily the impact of HIV/AIDS and poverty on the population under study.

Theoretical Concepts

Caregiving Concepts

In this section, I will examine current conceptualisations of caregiving as well as the distinction between objective and subjective burden.

A *caregiver* has been defined as "a person who provides direct care (as for children, elderly people, or the chronically ill)" (Merriam-Webster, 2005). There have been numerous studies describing the experiences of a range of caregivers and care-recipients. Examples include: spousal or family caregivers of Alzheimer's patients; family caregivers of mentally ill patients; female, elderly or family caregivers of HIV/AIDS patients; grandparent caregivers of children (including those affected by HIV/AIDS); and parent caregivers of HIV-positive children (Bowers & Myers, 1999; Caliandro & Hughes, 1998; Ferreira & Brodrick, 2001; Kosmala & Kloszewska, 2004; Linsk & Mason, 2004; Magana, Ramirez Garcia, Hernandez, & Cortez, 2007; Muthoni Kimemia, 2006; Orner, 2006; Potgieter & Heyns, 2006; Potterton, Stewart, & Cooper, 2007; Ssengonzi, 2007; Townsend & Dawes, 2004; Zarit, Orr, & Zarit, 1985).

Many of these past studies have been criticised for their tendency to focus on the negative aspects of caregiving while neglecting the positive and neutral aspects of the caregiving experience, leading to the creation of terms such as "caregiver burden," "caregiver strain," and "caregiver stress" (Hunt, 2003). *Caregiver burden*, for instance, has been defined in the

literature as a state resulting from the physical, emotional and financial demands of care which may be exacerbated by restrictions or discomfort to the caregiver in fulfilling normal roles (Hunt, 2003; Kinsella, Cooper, Picton, & Murtagh, 1998; Zarit, Reever, & Bach-Peterson, 1980). Some recent studies, as reviewed by Hunt (2003), have, however, placed more emphasis on positive aspects of the caregiving experience, leading to the creation of such terms "caregiver esteem," "caregiver satisfaction," and "finding meaning through caregiving." Studies with such emphasis have demonstrated that caregivers sometimes cope by finding meaning in the caregiving process (e.g., Farran, Miller, Kaufman, Donner, & Fogg, 1999).

It is therefore important to consider that responses to caregiving are complex and can consist of both positive and negative reactions to the role. Furthermore, when examining the response to caregiving it is important to distinguish between objective and subjective burden (Hunt, 2003). The *objective burden* associated with caregiving is defined as the observable, tangible costs to the caregiver (Jones, 2006). In contrast, the *subjective burden* associated with caregiving has been defined as the caregiver's personal appraisal of the situation and the extent to which the burden is perceived (Jones & Jones, 1994).

This then raises the question of whether an increase in objective burden invariably results in an increase in subjective burden. The relationship between the two concepts is complex. For instance, Jones (2006) found in a study of caregivers of patients with chronic mental illness that subjective burden is relatively low in response to the physical burden of tasks associated with caregiving (objective burden). However, when the care-recipient was uncooperative or demanding or if caregiving involved aspects that were embarrassing for the caregiver, subjective burden increased. Thus, in the above-mentioned study, the response of the care recipient to the caregiver's activities (objective burden) was described as a mediator that increased subjective burden. Other studies, such as one by Maurin and Boyd (1990, in Jones, 1996), also postulated that objective burden is predictive of subjective burden. However, the latter study further hypothesised that mediating factors such as social support and effective coping strategies might decrease subjective burden.

Significantly, subjective burden has been found to be the greater predictor of caregiving outcomes, and has been correlated with negative sequelae such as depression (Given et al., 1992) and increased risk of mortality in older spousal caregivers (Schulz & Beach, 1999). This finding has been confirmed by studies on co-resident caregivers of psychiatric patients

(Coyne et al., 1987; Noh & Avison, 1988). In further support of this assertion, it has been found that the manner in which the caregiver appraises the caregiving situation has an impact on caregiver outcomes – negative appraisals have been associated with higher caregiver burden, poor affect and minor psychiatric symptoms (Braithwaite, 2000).

The existing literature in this field therefore makes it clear that caregiving experiences and responses to them are complex and multi-dimensional. In summary, the literature has highlighted the following: the act of caregiving entails positive and negative dimensions for the caregiver; there are subjective and objective components to caregiver burden, with a complex relationship between the two; factors such as social support and care-recipient characteristics mediate the relationship between objective and subjective burden; and, subjective burden is a greater predictor of negative caregiver outcomes than is objective burden.

Models of Caregiving

The caregiver literature surveyed thus far dealt predominantly with the experiences of caregivers of patients and children with dementia, chronic mental illness, physical disabilities and cancer (Given et al., 1992; Jones, 1996; Raina et al., 2004).

Literature searches did not yield much information on quantitative studies of caregivers of orphans or vulnerable children (OVCs) or on theoretical frameworks guiding such interventions. There has recently been an increase in research focussing on elderly caregivers (see, e.g., Bowers & Myers, 1999; Caliandro & Hughes, 1998; Dowdell, 2004; Fuller-Thomson & Minkler, 2000; Hayslip & Kaminski, 2005; Joslin & Harrison, 1998; Landry-Meyer, Gerard, & Guzell, 2005; Linsk & Mason, 2004; Pinson-Millburn, Fabian, Schlossberg, & Pyle, 1996; Robinson & Wilks, 2006), and some authors have made suggestions as to theoretical perspectives from which to explore the phenomenon of grandparents raising grandchildren. For example, one might examine the socio-cultural changes that underlie custodial grandparenting (such as increased levels of child abuse, or increased death toll due to AIDS), or one might explore from the perspective of attachment theory the adjustments that the new family system will have to make (Hayslip & Kaminski, 2005; Raina et al., 2004). Despite these suggestions, there has not been much work on developing a coherent theoretical framework to guide further research and potential interventions aimed at improving the experiences of elderly caregivers.

Given this lack of theoretical grounding in the study of elderly caregiving, and particularly in the study of grandparents caring for grandchildren, I will draw on the relevant theories from community psychology as a framework for the current study.

Ecological Theory: People in context

Community psychology theories, specifically ecological theory, emphasise that people should not be studied without consideration of their contexts. According to Lewin (1951, in Orford, 1993), human behaviour is a function of the interaction between person and environment. For example, states such as anxiety and stress result from combination and interaction of the person (e.g., personality factors; learned ways of coping; needs; resource limitations) with the setting (e.g. resource limitations; lack of support). Therefore stress and associated negative outcomes, such as ill health, may occur if there is an absence of fit between the demands and resources of the person and the environment (Orford, 1993).

Furthermore, because people perceive, interpret and make meaning of their settings, strain may result from some other sources. For instance, it might result from an absence of fit between an individual's perception of herself (i.e., the subjective person) and that individual's perception of her environment (i.e., the subjective environment) as much as from an absence of fit between the objective person and the objective environment (Orford, 1993).

Also within community psychology, interpersonal systems theorists utilise similar principles, which they extend further to view individuals and behaviour as a function of the systems in which they exist. For instance, Bronfenbrenner (1979) proposed a "nested systems" model from which to approach research and intervention in communities. He conceptualised systems at four levels: *micro-*, *meso-*, *exo-* and *macro*-levels. The *micro-level* refers to systems the individual experiences directly and on a regular basis (e.g., home, school, or club). The *meso-level* refers to systems that consist of two or more of a person's micro-level systems and the links between them (e.g., home-school, home-club). The *exo-level* refers to systems with which the individual has no direct experience or interaction, but that have influence over his or her micro- and meso-level systems (e.g., local government structures, municipal structures). Finally, the *macro-level* refers to larger-scale systems that influence the ideology and social structure within which the person's micro-, meso-, and exo-levels operate (e.g., gender roles in society, policies towards the elderly, and prevailing discourses on HIV/AIDS) (Bronfenbrenner, 1979).

While most branches of psychology have traditionally focused on the interactions within, for example, the micro-system, community psychology has focused more on the interdependencies between the levels of a system (Orford, 1993). The current study aims to consider the impact of various system levels on the caregiving experiences of the selected population. While the focus will be on the micro- and meso-levels (such as caregivers' subjective reports on their caregiving experiences, perception of efficacy of support structures, and reported access to resources), consideration will also be given in this review to the impact of macro- and exo-levels on the individual's experience (e.g., the spread of HIV/AIDS and its impact on population demographics and family structure; government policies at an exo-level, which influence access to the old age pension and basic amenities at a micro-level; and, briefly, prevailing ideologies regarding HIV/AIDS and stigma which may impact on stress levels, disclosure and help-seeking on a micro-level).

The Impact of HIV/AIDS on Demography and Families

From a community psychology perspective, and particularly from Bronfenbrenner's (1979) nested systems perspective, any attempt to understand the experiences of caregivers in South Africa would not be complete without a consideration of the context within which they find themselves. I will therefore examine the main contextual issues from a regional and national perspective (the exo- and macro-levels), before focussing on the situation at the household level (the meso- and micro-levels).

On the macro-level the public health factor that is particularly germane to the current study is the spread of HIV/AIDS, which has reached pandemic proportions in sub-Saharan Africa. Although the region is home to only 10% of the world's population, approximately 2/3 of the world's HIV infected people are in sub-Saharan Africa, and 76% of those who died of AIDS-related causes in 2007 lived in this region (UNAIDS, 2005, 2007). South Africa has the largest HIV-positive population in the world (UNAIDS, 2007). This public health crisis has important implications for population demographics and, consequently, family structure in the region and this country.

The spread of HIV/AIDS has resulted in changes in the demography of the South African population. Amongst Southern African countries, South Africa has been reported to have the highest proportion of elderly people in its population (Kinsella & Ferreira, 1997). Furthermore, over the past 30 years there have been decreases in both fertility and mortality in the South African population. With the additional impact of HIV/AIDS, there have been

indications of population ageing within the African sub-category of the South African population (Ferreira & Gillis, 1997; Udjo, 2006). HIV/AIDS has been shown to have a greater impact in decreasing the growth of the young compared to the elderly African[1] population group in South Africa (Udjo, 2006).

Studies have demonstrated that the impact of the HIV/AIDS pandemic is most profoundly felt in the most vulnerable sectors of society: women, the poor, and children (Gilbert & Walker, 2002). The previously disadvantaged of South Africa, Africans, have been found to be the highest at-risk group (Shisana et al., 2005). This at-risk status has been linked to the poor socio-economic conditions under which such individuals live. For example, in a survey of 771 households affected by HIV/AIDS in South Africa, it was found that 44% of households had a monthly income of less than R1000 (Steinberg et al., 2001). The financial need of households, in turn, impacts on their access to medical treatment and to good nutrition.

In sub-Saharan Africa, and in developing countries generally, the pattern of HIV/AIDS infections has been demonstrated to be different to that in developing countries: there are high infection rates in the general population and a large percentage of those infected are female (Gilbert & Walker, 2002). Recent statistics indicate that females make up 61% of the region's HIV infected population (UNAIDS, 2007). Similarly, in South Africa, women are worst affected by the virus. HIV prevalence amongst South Africans 2 years and older was 10.8% in 2005 with a prevalence of 13.3% in females and 8.2% in males. Further, within the 15-24 year age group, the incidence of the virus was found to be eight times greater in South African females than males.

The middle generation (15-49 years), which make up the majority of the work-force of a country, have been singled out as at particularly high risk for infection and death due to

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[1] Under apartheid law the South African population was classified according to racial groups. The terms African, White, Coloured and Asian/Indian are still commonly utilised in South African literature today. Their use, in the literature surveyed, and in this review, is intended to acknowledge that the effects of past social inequalities in South Africa remain. Therefore the term African, in this review, denotes the black African racial sub-group in the South African population, unless otherwise qualified.

HIV/AIDS. For adults in that age range, the HIV prevalence rate was estimated at 16.2% by Shisana et al. (2005); Dorrington, Bradshaw, Johnson, and Budlender (2004) reported that 70% of deaths in that age group in 2004 were HIV/AIDS-related.

Therefore, in South Africa, middle-aged African females are the most at-risk group for HIV infection. This status has multiple implications for the future of both children and families in South Africa. For instance, children run the risk of infection, either by mother-to-child transmission or due to abuse or cross-contamination. Furthermore, children may be left unattended at home or in the care of older children in the household. Illustrating this point, in a recent large-scale survey of South African households, 2.6% of children identified themselves as the head of the household. By extrapolation, this implies that 180 433 South African households are child-headed. Further, schooling, especially that of female children, may be interrupted in some cases. The above-mentioned study found that 7% of female caregivers were under the age of 18 (Shisana et al., 2005).

The stress on the families of those who are infected is intensified. For instance, there is often a shift of the responsibility held by the ill/deceased parent on to others in the family, thus placing a greater burden on immediate and extended family members and social networks. During the course of the illness and in the event of the death of an adult in the family, the care of their children often falls to the extended family network or grandparents (Shisana et al., 2005).The impact on families has, in turn, further residual impacts on children, due to the greater levels of burden in the households in which they reside.

The burden is felt most greatly in the loss of income that the ill/deceased member may have contributed (Nattrass, 2004; Steinberg et al., 2001). Further, with the onset of the illness, there are greater medical costs and the financial burden on the household is increased. Ill family members require caregiving, especially during the later stages of their illness. Duties of the caregiver may include assistance with basic tasks such as bathing and eating (Steinberg et al., 2001). Family members, usually female, assume the responsibility of caring for the ill. For example, of the caregivers surveyed by Shisana et al. (2005), 68% were female, of which 23% were over 60 years of age.

The responses of the broader community may also impact on the ability of households to cope optimally. In some cases the family has also to cope with stigma and hostility from the

community because of the HIV status of one of its members (Deacon & Stephny, 2007; Skinner & Mfecane, 2004; Steinberg et al., 2001).

For the purposes of this study I will focus on two salient aspects of the impact that HIV/AIDS has on social structures: the plight of the orphans and vulnerable children (OVCs) of the AIDS epidemic; and the burden of care on family members (particularly grandparents) and social networks.

Orphans and Vulnerable Children (OVCs) of the AIDS epidemic

There have been studies[2] on the direct (Brookes, Shisana, & Richter, 2004) and indirect impact (Bray, 2003; Foster, Levine, & Williamson, 2005; Makame, Ani, & Grantham-McGregor, 2002; Monasch & Boerma, 2004; Sengendo & Nambi, 1997; Wild, Flisher, Laas, & Robertson, 2002) of HIV/AIDS on children both in the developed and developing world. There is also a growing body of literature focusing on responses to the problem (Crewe, 2001; Frohlich, 2005; Giese, Meintijies, Croke, & Chamberlain, 2003; Ngalazu-Phiri & Tolfree, 2005; Richter, Manegold, & Pather, 2004; Richter & Rama, 2006). In understanding the impact of caregiving on the elderly and in formulating appropriate responses to support them, it is imperative to gain an understanding of the psychosocial challenges facing the children under their care. However, as the focus of my study is on elderly caregivers, my review of the OVC literature is brief and focused only on the psychosocial impact of the HIV/AIDS epidemic on children, utilising literature most salient to the South African context.

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[2] There have been criticisms, to a degree, about the quality of data collected in South African surveys, specifically HIV/AIDS studies. These weaknesses have been attributed to, amongst other factors, a difficulty in extricating the impacts of HIV, rural-urban migration and modernisation on household composition; the lack of a consistent definition of the terms "head of the household," and "OVC" (which is sometimes defined as <15 years and at other times <18years); and inaccuracies in population estimates and incorrect registration of information. However, importantly, it has also been pointed out that the studies reviewed are the only data sources available, and despite the shortcomings, yield valuable information (Gilbert, 2002; Merli & Palloni, 2006).

A Definition of Orphans and Vulnerable Children

Orphanhood has been defined as the loss of one or both parents before the age of 18 years to death, desertion or other means (Skinner et al., 2006). In 2004, there were 626 000 AIDS-related maternal orphans in South Africa (Dorrington et al., 2004). These children experience emotional, material, and social problems (Andrews, Skinner, & Zuma, 2006; Freeman, 2004). For instance, Cluver and Gardner (2006) showed, in a study of Cape Town orphans, that those children were more likely than non-orphans to have concentration difficulties, somatic symptoms and frequent nightmares.

Aside from children who have actually lost their parents to HIV/AIDS, those who have ill parents, live in poor households, or who are discriminated against because they or their parents are HIV-positive, are vulnerable to the same material, emotional and social problems as mentioned above (Skinner et al., 2006). It has also been argued that HIV/AIDS and poverty in the South African context are inextricably linked and that research and policy interventions should therefore focus on all vulnerable children (Richter, 2004). Therefore an inclusive term, *orphans and vulnerable children (OVCs)* has been proposed in reference to such children (Skinner et al., 2006).

The Impact of HIV/AIDS on OVCs in South Africa

Emotional problems often develop in OVCs because the process of grieving following death from HIV-related causes is complicated and prolonged. Levels of stress start to rise during the parent's illness, and children may experience anxiety and uncertainty over the fate of their parent over a period of months or longer (Freeman, 2004; Townsend & Dawes, 2004). The ensuing death of the parent is almost invariably followed by feelings of loss and sadness together with an increased risk of depression, anxiety and adjustment difficulties (Freeman, 2004; Richter, 2004; Wood, Chase, & Aggleton, 2006). Furthermore, in communities with high vulnerability to HIV/AIDS, children may, over the course of a few years, witness multiple deaths in their immediate and extended families and across their community, exacerbating the emotional problems associated with bereavement (Townsend & Dawes, 2004).

In addition to emotional issues directly associated with bereavement, in some cases OVCs also have to contend with the emotional burden of helping younger siblings to deal with their grief. This burden is frequently aggravated by the fact that they may be facing the fear that they may have been infected with the illness themselves (Richter, 2004; Wood et al., 2006).

Families do not always have the skills or resources to respond appropriately to the emotional difficulties experienced by OVCs. For instance, illness and death may be explained to the children in indirect terms, which may impact on their ability to effectively negotiate the mourning process. In certain communities, silence and non-expression of grief is seen as good and as a sign of perseverance; subsequent rebelliousness, which may be understood as an external expression of grief, is then viewed as unacceptable by caregivers (Wood et al., 2006).

Societal responses to the emotional difficulties experienced by OVCs are similarly not always helpful or supportive. In some studies, OVCs have reported some degree of stigma from their communities. While this may not always be the case (Chimwaza & Watkins, 2004), where it does happen it can lead to social isolation, which may cut children off even further from sources of support (Deacon & Stephny, 2007; Freeman, 2004; Simbayi et al., 2006; Skinner & Mfecane, 2004).

With regard to material problems, the parent's illness has a financial and social impact on the family (Wood et al., 2006). Parents are less able to care for their children due to HIV-related illness, and OVCs may therefore have to take on added responsibilities (including providing care for their parents) (Andrews et al., 2006; Richter, 2004). They may drop out of school to do so, and may thus experience a disrupted education (Wood et al., 2006). Furthermore, after the loss of their parent(s), OVCs may become members of child-headed households, with the accompanying risks of poor nutrition and poverty. OVCs in these situations may also assume risks to their physical well-being because they have a higher likelihood of living on the streets and/or becoming victims of exploitative child labour (Foster, 2000; Richter, 2004). Further social problems may arise due to frequent changes in their living arrangements. OVCs may be subjected to multiple moves, caregiver changes and illness in their caregivers. This may place them at risk for unfair treatment or abuse within their new homes. They may also experience disrupted relationships with members of their extended family as a result (Cluver & Gardner, 2007; Richter, 2004).

Importantly, the following protective factors for the psychosocial well-being of OVCs have been identified: boundaries and discipline; feeling loved, respected and wanted; the presence of friends; community psychosocial programmes: and prayer (Cluver & Gardner, 2007; Wood et al., 2006).

The Changing Role of the Extended Family in the Care of OVCs

Given the risks that OVCs face, it is important to understand the role that the family and extended networks play in their care. The role of the family in the care of children is changing. Traditionally in African families children were often raised by adults other than their biological parents due to, for example, political or economic reasons. Aunts and uncles were seen as the "traditional safety net" for the care of children, with more distant relatives and grandparents constituting the "alternate safety net" (Foster, 2000, p 57). Due to the recent increases in Westernisation, migration, and opportunities for formal education, together with the saturation of traditional sources of care (families often have more than one OVC under their care), the traditional network of support has been weakened. This has resulted in increased dependence on the alternate networks of grandparents and distant family (Foster, 2000). Although fostering and adoption are possible alternate avenues of care for OVCs (Townsend & Dawes, 2004), current evidence indicates that the extended family still bears much of the responsibility of care (Foster, 2000; Simbayi et al., 2006), with much of that responsibility falling on grandparents. While Foster (2007) has reported on the resilience of communities in their response to the epidemic and the importance of community safety nets in assisting HIV/AIDS impacted households in sub-Saharan Africa, he has also acknowledged that these networks operate under severe resource limitations. It is therefore important to further understand the challenges that elderly caregivers face. As a starting point, I first focus on the general challenges that the elderly in South Africa face, and then examine how these challenges have been exacerbated by the impact of HIV/AIDS and by the consequent orphan crisis.

The Elderly in South Africa

The Process of Ageing

Defining the concept of ageing is not a simple matter. *Ageing* has been defined in the literature as the "accumulation of diverse adverse changes that increase the risk of death" (Harman, 1998, p. 1). It may be further classified into *primary ageing*, which refers to processes that are "intrinsic to the ageing process that are ultimately irreversible" (Birren & Schroots, 1995, p. 10) and *secondary ageing*, which refers to "changes caused by illnesses that are correlated with age but [that] may be reversible or preventable" (Birren & Schroots, 1995, p 10). Further differentiations have been made between normal and successful ageing. *Successful ageing* has been defined as ageing under "development enhancing and age-friendly environmental conditions" (Baltes & Baltes, 1990, in Smyer & Qualls, 1999, p. 4).

Although *normal ageing* cannot be simply defined, conceptually it refers to ageing "without biological or mental pathology" (Baltes & Baltes, 1990, in Smyer & Qualls, 1999, p. 4). Therefore, although intrinsic ageing processes are unavoidable, the manner in which one experiences old age depends on various factors (e.g., socioeconomic status, current and past physical and mental health, and functional abilities) and how these have varied across a person's lifetime.

According to statistical definitions, it is clear that certain chronic illnesses such as arthritis are typical of the experience of ageing and are therefore considered "normal" in the elderly (Smyer & Qualls, 1999). For my purposes I will focus on statistically prevalent illnesses in the elderly.

Ageing is associated with a variety of physical and cognitive changes. For instance in older adults there is a loss of height and body weight, stiffening of joints, shrinking of organs (resulting in decreased adaptation to stress), increased blood pressure and decreased cardiac output and deterioration in vision and hearing (Albert & Cattell, 1994; Kumar & Clark, 1998; Zarit & Zarit, 2007). Memory and higher-order cognitive functions such as problem solving and abstract reasoning show declines, although cognitive change in general occurs at a variable rate in the elderly and does not always visibly impact on an individual's adaptive functioning. Depression is not invariably associated with ageing, but the elderly are at high risk for developing symptoms of the illness as a result of possible micro- and meso-level changes, for example in physical and social functioning (e.g., death or illness in peers and subsequent shrinking of the individual's social network) (Smyer & Qualls, 1999; Zarit & Zarit, 2007).

The process of ageing can therefore be a challenging one, with an increased likelihood of physical and cognitive impairment. The manner in which the elderly cope with these challenges depends on factors over their lifetime, such as their past and present financial, physical and social situations. For example, Gilbert and Soskolne (2003) demonstrated that the self-reported health of the African elderly in Soweto is impacted by their perception of their environment and access to social resources. At exo- and macro-levels, the broader context in which the elderly find themselves is equally important, as it may impact on the individual factors listed above, and thus on the ability of the individual to age successfully. Examples of such factors may be the prevailing ideologies regarding certain social or racial groups, socio-economic inequalities, the political or economic climate of the country, or

government policy which may or may not consider the specific needs of the elderly. This context differs widely between developed (and more resourced) and developing countries. In the following sections I will first briefly outline South African government policies affecting the elderly and then review studies that examine the experience of the elderly in the South African context.

South African Governmental Policy regarding the Elderly

It is beyond the scope of this paper to exhaustively review policy responses concerning the elderly in the HIV/AIDS context. Below, I briefly touch on ways in which the needs of the elderly are supported and addressed by the government, as well as gaps that are yet to be filled.

South Africa is one of three countries in Sub-Saharan Africa (the other two are Namibia and Botswana) that offer a non-contributory social pension to the elderly on a large scale. In South Africa the government old age pension[3] is means tested. Women are eligible for the pension at age 60 and men at age 65 (HelpAge International/International HIV/AIDS Alliance, 2003). The old age pension has played an important role in poverty alleviation in HIV/AIDS-affected households, as will be demonstrated later in this review. However, it has been argued that the contribution of the old age pension to minimising economic hardship in such households has not been sufficient and that other avenues for reducing poverty in HIV/AIDS affected households need to be explored (Legido-Quigley, 2003). To this end, the introduction of a basic income grant for all South Africans has been argued for (Legido-Quigley, 2003; Nattrass, 2005).[4] Further, it has also been demonstrated that social grants may

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[3] At the time of the study the government old age pension amounted to R870 per month (South African Social Security Agency, 2008). Historically, this grant was initially intended only for the poorest White South Africans. Later, it was introduced at variable values, according to racial classification, for all South Africans. It was introduced at an equivalent value to all deserving South Africans in 1993 (Merli & Palloni, 2006).

[4] Other potential sources of income for poverty afflicted South African households include: the child support grant, a means tested grant to the value of R200 per month, available to citizens who are the primary caregiver of a child less than 14 years of age; the foster care grant, of R620, available to the legal guardian of a child (however it is difficult to obtain due to lengthy legal procedures); the disability grant, dependant on a supporting

be difficult to access by certain communities, especially in the rural areas (Booysen, 2004; Ferreira, Keikelame, & Mosaval, 2001).

The South African government has demonstrated awareness of the need to respond to the unique needs of the elderly in the country's current socio-political and economic context. Current South African legislation regarding the elderly, The Aged Person's Act of 1967, is outdated. The government is in the process of drafting a Bill on the status of older persons in the country, with proposed recognition of the place of the elderly within communities and their changing roles (breadwinners; caregivers; second-time parents). The primary objective of the legislation is the provision of affordable, accessible and equitable services to the elderly (South African Social Security Agency, 2008).

Internationally, there have been various documents drafted that demonstrate increasing recognition of the role and vulnerabilities of the elderly as caregivers, including the following: The United Nations Madrid International Plan of Ageing (United Nations, 2002); The African Union Policy Framework and Plan of Action on Ageing (African Union/HelpAge International, 2003); The Commission for Africa Report (Commission for Africa, 2005); the Gleneagles G8 Summit Communiqué (2005); and the United Nations World Summit in New York (United Nations, 2005). However, while these documents provide useful guidelines for policy-makers, they do not provide a coherent policy framework that inclusively addresses the specific needs of the elderly. Two more recent documents, The United Nations Policy Framework on HIV/AIDS and Family Well-being (United Nations, 2004) and the Valletta Declaration on HIV/AIDS and Older People (HelpAge International/International Institute of Ageing, 2005) provide more detailed outcomes that are relevant to policy making in sub-Saharan Africa, and that recognise the role of the elderly within families and communities.

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medical report, (an HIV positive person, for example, is only eligible for the grant in stage 4 of the illness and loses the grant once their health improves due to anti-retroviral treatment), to the value of R870 (Legido-Quigley, 2003; Nattrass, 2005; South African Social Security Agency, 2008). The proposed value of the basic income grant has been R100 – R200 (Legido-Quigley, 2003; Nattrass, 2005).

There has been criticism leveled against South African policy makers for the lack of a consistent policy framework that addresses the needs of the elderly within the context of the HIV/AIDS pandemic (Ferreira, 2006). Drawing on the above documents, a rudimentary framework has been proposed by Ferreira (2006), which addresses the impact on the elderly at the micro-, meso-, exo-, and macro-levels. The proposed framework has three intersecting aspects: reducing the vulnerability of the elderly to the HIV infection and to the impact of the epidemic; recognising and supporting the contributions of the elderly; and formulating integrated responses to the epidemic that include the elderly.

It has therefore been highlighted that while some economic relief exists for the elderly at a governmental level, given the HIV/AIDS context and extreme poverty, it is far from sufficient. Further, policy responses to the HIV/AIDS epidemic need to integrate the contributions and needs of the elderly.

Challenges Facing the South African Elderly

South Africa's population has in the past been split along racial lines with accompanying socio-political inequalities. As a result there exist segments of the population with characteristics similar to that of people in developed countries and a large majority with socio-demographic characteristics consistent with developing countries. It has been reported that, in 2005/6, 10% of the South African population earned more than 50% of the household income in the country while 40% of the population earned less than 7% of household income (Statistics South Africa, 2008). Impairments associated with the normal process of ageing are therefore exacerbated in disadvantaged segments of the South African population by poor infrastructure and relative lack of resources. For the purpose of this research I will focus on the disadvantaged African population group.

Therefore the experience of growing older in South Africa is not necessarily one in which the elderly can expect increased care, support and reduced responsibility. In fact, studies[5] have demonstrated that the trend amongst the African population appears to be the converse. In African households in South Africa, the elderly often face increased social, caregiving, and

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[5] The studies reviewed below utilise various age descriptions of what constitutes the "elderly." This ranged from 50 - 65 years across studies (Makiwane & Kwizera, 2006; May, 2003; Møller & Ferreira, 2003).

physical responsibilities, have to take on increased financial burdens, and face an increased risk of abuse. All of these factors exact a telling emotional toll (May, 2003; Makiwane & Kwizera, 2006; Møller & Ferreira, 2003).

Increased Social Responsibility

Traditionally the African elderly enjoyed the support of the extended family network and often resided with their eldest child (Møller & Devey, 1995). However, more recent census data indicate that while 58% of African elderly live in multi-generational households, they are also more likely than other racial groups in South Africa to be head of the household[6] in which they reside (Noumbissi & Zuberi, 2001). This trend is prevalent across genders, with 60% of older African females taking on head of household responsibilities, despite the fact that this responsibility has not traditionally been assigned to women (Makiwane & Kwizera, 2006).

The trend toward elder, female-headed households, although recently on the increase, is not a new one and its reasons may be attributed to past and present migratory trends, modernisation and the impact of HIV/AIDS. Historically, there was prevalent rural-urban migration amongst African men, who left their homes and families in search of work under apartheid law and often did not return to their rural homes in old age. Furthermore, there has, in more recent years, been an increase in widowhood amongst African women due to the deaths of their husbands from AIDS or other causes (Mba, 2003, in Mba, 2005), leading to an increasing imbalance in the ratio of females to males reaching old age (Noumbissi & Zuberi, 2001). More recently, modernisation and increased rural-urban migration amongst the younger generation, including women and children, and an increase in mortality amongst the middle generation, has resulted in an increase in the number of rural elderly being left to care for themselves and, at times, their ill children and/or grandchildren (Makiwane & Kwizera, 2006; Merli & Palloni, 2006; Smit, 2001). A recent study reported an increase in the proportion of the elderly living with orphaned children in the areas of highest HIV prevalence in South Africa. However, it has also been found that it is difficult to extricate which factors (migration, modernisation, and/or the impact of HIV/AIDS) are responsible for the changes in household composition (Merli & Palloni, 2006).

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[6] "Head of the household" has been defined as the person who assumes the responsibility for making decisions in the household (Statistics South Africa, 1998 in Mba, 2005).

Increased Caregiving and Physical Responsibilities

Although African women in South Africa are relatively more prone than women from other racial groups in South Africa to illnesses such as depression, hypertension and diabetes, their physical exertion within the household does not appear to lessen with old age (May, 2003). As noted above, many of the elderly function as caregivers within their families. Makiwane (2004) found that 20% of the elderly population surveyed (of whom the majority of respondents were African) in the Mpumalanga province were caring for grandchildren under 6 years of age, and 46% were caring for children between the ages of 6 and 18 years. These individuals also remained responsible for domestic work within the home. This trend is confirmed by other studies (e.g., Møller & Ferreira, 2003), which have found that the highest concentration of care for ill family members is in urban black households, followed by rural black households.

Increased Financial Burden

The elderly in South Africa often play an important financial role in their families (Legido-Quigley, 2003) due to the high rates of unemployment amongst the middle generation as well as illness and death due to HIV/AIDS. This is despite the fact that, globally, the elderly are amongst the poorest members of society, and that, in South Africa, older African households are the poorest.

Given this situation, very few African pensioners are able to use their pension income on themselves (Møller & Ferreira, 2003). A study in rural and urban areas of the Mpumalanga province found that 72% of elderly people were the main breadwinners in multi-generational households, spending their income on household necessities (including food, clothes and medical treatment), grandchildren's education, and funeral expenses (Makiwane, 2004). Other studies confirm this trend: For instance, May (2003), in a review of existing literature, including an analysis of secondary data from two national cross-sectional studies, described how pension sharing impacted on living arrangements and family relationships (see also Merli & Palloni, 2006; Møller & Devey, 1995, 2003), while Schatz and Ogunmefun, (2007) described how the pension income of grandmothers living in the rural town of Agincourt assisted families in meeting daily needs and overcoming crises. However, while Makiwane (2004) viewed pension sharing as a drain on the resources of the elderly, May (2003) described it as conducive to the social integration of the elderly.

Increased Risk of Abuse

The current elderly African population were subject to discriminatory apartheid policies in their youth and are therefore generally of a low socio-economic status with low levels and quality of education (Makiwane, 2004). This situation places them at particular risk for further exploitation and abuse. Studies have found that elderly African individuals are subject to psychological, emotional, or financial abuse and general maltreatment within their homes (May, 2003). Further, the elderly, particularly females, are subject to discriminatory cultural practices which decrease their status within the family. Many respondents to the Mpumalanga survey felt unable to discipline their children or grandchildren and felt that the younger generations were unappreciative and disrespectful (Makiwane, 2004).

The levels of social, physical, caregiving, and financial responsibilities, as well as the increased risk of abuse, faced by elderly African individuals in South Africa have a demonstrable impact on emotional functioning. For instance, these individuals are prone to loneliness, depression, sadness, worry and anxiety, and express dissatisfaction with their lives (Makiwane et al., 2006; Møller et al., 2003). Nonetheless, it is also important to note that despite these challenges, family, marriage, a home and income source, as well as religious beliefs, have been listed as positive aspects in the lives of rural and urban elderly African people (Makiwane et al., 2006).

The experience of ageing is challenging, and is made even more so in the South African context of poverty and deprivation. It is from within this context that African South African elderly often take on the responsibility of providing care to OVCs and their ill adult children. Knowledge of their experience of, and responses to, these caregiving roles is essential in formulating interventions and policies to assist these individuals. Also of interest is the way in which the experiences of elderly caregivers differ between the developed and developing world.

Caregiving in Old Age: North American research

Even in First World developed countries, there has been a dramatic increase in the number of grandparents raising grandchildren in the last decade (Casper & Bryson, 1998). While the phenomenon of grandparent caregiving is not specific to a single age, socioeconomic or ethnic group (Pinson-Millburn et al., 1996), in the United States, epidemiological studies

have shown that long-term custodial caregiving is most predominant amongst African-American grandmothers from low-income households (Fuller-Thomson, Minkler, & Driver, 1997). The reasons for these caregiving arrangements range from unemployment, divorce, and abuse to HIV-related causes and death of the parent, and may be on a long-term or short-term basis (Pinson-Millburn et al., 1996).

Both quantitative (Bowers & Myers, 1999; Dowdell, 2004; Landry-Meyer et al., 2005; Mills, Gomez-Smith, & De Leon, 2005) and qualitative (Caliandro & Hughes, 1998; Linsk & Mason, 2004; Robinson & Wilks, 2006) studies[7] in North America have documented the negative effects of caregiving on the physical capabilities of grandparents. These effects include: higher risk for developing mental health problems, including depression; and an impaired ability, relative to non-caregiver grandparents, to successfully complete activities of daily living (Robinson-Dooley & Kropf, 2006). Caregivers also reported on the emotional burden associated with caregiving. These reports included concerns regarding the effectiveness of their parenting skills, concerns for their own health, difficulty managing multiple tasks, stress over a lack of personal time and worries about the future of the children under their care. Given the high risk for negative sequelae it is not surprising that caregivers were found to be more in need of, and more likely to frequently use, social services (Linsk & Mason, 2004).

North American studies have also identified risk factors for the experience of caregiver stress in grandparents. These risk factors include the presence of a trauma which precipitated taking on the role (such as the death of a child); full-time as opposed to part-time care; behavioural problems in the child; and poor health in the caregiver or the child (Dowdell, 2004). African-American, low-income groups without financial or medical aid were found to be at greater risk for psychosocial distress (Bowers & Myers, 1999).

Nonetheless, despite the financial, physical and emotional hardship associated with caregiving, there has been evidence, particularly in the American population of grandparent caregivers of HIV positive children, of positive aspects to caregiving (e.g., pride at commitment to family, and lack of regret over taking over the caregiver role). For instance, in

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[7] These studies focussed generally on grandparent caregivers and did not focus on specific caregiver groups such as caregivers of abused children or HIV infected children.

one small (n = 10) qualitative study, grandmothers stated that caring for the child brought joy to them, and reported a strong bond between themselves and the child (Caliandro & Hughes, 1998).

In summary, North American studies reveal that grandparents from lower income, historically marginalised groups are more likely to take on the role of caregiver to their grandchild(ren). Further, given the context of deprivation, they are most susceptible to the negative sequelae of caregiving in old age. In developing countries, economic deprivation and poor infrastructure certainly impact negatively on the process of ageing, and the abovementioned challenges and burdens inherent in caregiving are even further exacerbated by changes in family structure as a result of the HIV/AIDS pandemic (HelpAge International, 2005a, 2005b).

Caregiving in Old Age: Developing world and African research

Unlike the studies reviewed in the previous section, those reviewed in this section mainly used qualitative methodologies and were exploratory in nature. Nonetheless, some common themes emerged.

Women as the Primary Caregivers

Studies overwhelmingly indicated that women bear most of the responsibility for care. A survey of "foster" caregivers in Zimbabwe revealed that caregivers in the survey were mainly female, poor and unmarried. More than half (53%) of those providing care to OVC's were grandmothers (Howard et al., 2006). This was confirmed by a study in Togo which found that most caregivers were female with an average age of 60 (Moore & Henry, 2005). In Uganda, however, where the epidemic reached its peak in the early 1990s, families have shown remarkable resilience in the manner in which the division of labour in the home has evolved. Recent studies have shown that, even though caregivers are still mainly female and elderly, men were increasingly taking on household roles that had in the past been relegated to women (Kakooza & Kimuna, 2005; Ssengonzi, 2007).

Caregiving in the Context of Scarcity

Caregiving occurred in the context of limited resources, poor health infrastructure and consequently poor access to health care (HelpAge International, 2005a, 2005b; HelpAge International/International HIV/AIDS Alliance, 2003; Kakooza & Kimuna, 2005; Ssengonzi, 2007). A notable exception with regard to adverse contextual factors is that of Thailand. State

health insurance is available, and there have been successful HIV awareness and education campaigns in the country. However, formal support for people living with HIV/AIDS was still absent (Knodel, 2005).

Personal Sacrifices by Caregivers

Of note are the personal sacrifices that caregivers make in order to fulfil their roles. The tendency to neglect their own needs in order to see to those of their families was found across several studies. The sacrifices made were found to take a toll on caregivers' health and financial status (HelpAge International, 2005a, 2005b; HelpAge International/International HIV/AIDS Alliance, 2003; Kakooza & Kimuna, 2005; Moore & Henry, 2005; Ssengonzi, 2007).

A study in Uganda found that females, who were the majority of caregivers, had a poorer health status than males. It is most likely that this was the case because caregivers neglected their own health and needs in order to care for their family, as seen in Cambodia (HelpAge International, 2005b). A study in Thailand gave further insight into the lifestyle changes experienced and sacrifices that elderly caregivers made, in for example, resuming the responsibility for household chores while battling illnesses such as arthritis (HelpAge International, 2005a).

Caregiving also exacted an emotional toll on caregivers, who reported anxiety about their future well-being, and grief at the loss of their children. Caregivers in HIV/AIDS affected households were at high risk for infection themselves (Kakooza & Kimuna, 2005; Knodel, 2006; Ssengonzi, 2007; World Health Organisation, 2002). It was also found that they were at risk for burnout, and for being the victims of stigma, violence and abuse (World Health Organisation, 2002).

Financial sacrifices were also made, in the sale of household assets, to alleviate the high costs of caregiving (HelpAge International/International HIV/AIDS Alliance, 2003; Knodel, 2006).

It has been argued by Knodel (2006) that as access to anti-retrovirals increase, the concomitant delay in serious illness and death may change the role that the elderly play within households – that is, they may shift from providing terminal care to ensuring adherence to medication and treatment regiments.

Protective Factors

Contributions Made by the Elderly in Communities

There was evidence of factors that may be seen as protective for elderly caregivers. The elderly in, for example, Thailand were found to play an important role within their homes and in their communities, by educating others and advocating for change, acceptance and increased support (HelpAge International, 2005a). This role may function to increase their sense of agency and foster hope that circumstances may improve. In one of the few quantitative studies on caregivers in Africa, which included older caregivers, it was found that lower levels of hope were associated with higher levels of burden in caregivers. The same study found that older caregivers and caregivers with higher educational levels reported lower caregiver burden (Muthoni Kimemia, 2006).

The impact on caregivers was common across all studies reviewed: they experienced financial, physical and emotional stress, and concern for their future health and well-being as well as for the future of the child. Psychological sequelae included worry, depression, and feelings of hopelessness.

Caregiving in Old Age: South African studies

Although there have been numerous South African studies focusing on the experience of ageing in the country, and on the impact the HIV/AIDS pandemic has had on children (Bray & Brandt, 2005; Cluver & Gardener, 2007; Richter, 2004), there is comparatively little local research on the impact on family members (particularly elderly female family members) who provide care to the ill and OVCs. The local research that has been conducted has been primarily qualitative in nature, has focused on the experiences of caregivers to HIV/AIDS patients, and has seldom focused on the experience of the elderly as caregivers to OVCs. In this section, then, I will closely review studies that are most relevant to my topic of interest (viz., elderly caregivers). However, due to the limited number of studies on elderly female caregivers of OVCs, my focus in this section of the review is more broadly on older adults as caregivers of persons in households impacted by the HIV/AIDS pandemic.

Females as the Primary Caregivers

Orner (2006) conducted a recent household survey study in some of the low socio-economic status areas in and around Cape Town (Khayelitsha, Gugulethu and Delft). Forty-five family

caregivers (average age: 40 years) of HIV/AIDS patients were interviewed; of these, 43 were female, indicating once more the disproportionate burden placed on women in affected communities (Akintola, 2006; Ferreira & Brodrick, 2001). The gendered division of labour in HIV-affected households has various possible causes. Men were either absent from the household (sometimes due to absconding) or unwilling to assist. This gendered division of labour was found to be perpetuated by cultural stereotypes: It was found that men in the household may refuse to assist with traditionally female assigned tasks such as caregiving or household chores; women reported that it was normal for men not to help, and that men were not suited by nature to fill the caregiving role. Men who did take on the role were at risk for being teased and insulted by community members (Akintola, 2006).

Factors Associated with Increased Caregiver Burden

Socioeconomic Factors

Ferreira et al. (2001) conducted a longitudinal survey study of 43 Cape Flats grandmothers (aged 50-79 years) who were caregivers to an adult HIV-positive child and at least one co-resident grandchild, who may or may not have been HIV-positive. Participants were followed up on three occasions at 3-month intervals. The researchers focused primarily on changes in the coping ability of the caregivers, changes within the household, and changes in the status of the HIV-positive adult.

The primary finding was that the grandmothers experienced a tremendous financial burden as a result of their caregiving responsibilities. All of the households surveyed lived in extreme poverty; neither the ill adult (due to the illness itself) nor the older caregiver (due to caregiving responsibilities) were able to secure or retain a job, and the male breadwinner had, in many cases, absconded upon learning of another family member's illness. Therefore, in most cases, the grandmother's monthly old age pension was the only regular source of income (and only half of the 43 participants actually qualified for such a pension). Because of this fact, and the fact that respondents stated that they found it difficult to apply for a child support grant from the government, household income was supplemented by loans, by the sale of second-hand clothing or sweets, and by money borrowed from neighbours.

The impact of these dire financial straits was felt most greatly in the form of food poverty. Participants perceived good nutrition as essential for HIV-infected individuals, but finding food for members of the household proved to be a daily struggle for the grandmothers.

Money was also required to provide transport to clinics for medical treatment, for the educational needs of children in the household, and for the funeral insurance of the dying.

More recent studies on the experiences of the elderly, which included elderly caregivers, in Mpumalanga and Agincourt (rural north-eastern South Africa) reported similar findings (Makiwane, Schneider, & Gopane, 2004; Ogunmefun & Schatz, 2006). The Agincourt study found that elderly caregivers utilised their pension money for the well-being of care-recipients at the expense of their own needs. They also sold household assets and incurred debts in order to provide for the needs of the household (Ogunmefun & Schatz, 2006). The extent of the financial impact was highlighted in the study by Ferreira et al. (2001) which reported on caregivers' perceptions that input on business skills would better improve their ability to cope more than would information on caregiving skills.

There was also evidence of indirect financial impacts on households as a result of caregiving, resulting in increased burden on the household and consequently, the caregiver. Caregiving, it was discovered, was time-consuming and impacted negatively on caregivers' employment status, as well as on time spent on potential income generating activities such as farming and trading. The consequent severe financial difficulties increased caregiving-related stress (e.g., because of lack of electricity, cooking became difficult; because of transportation difficulties, clinic visits became difficult) (Ogunmefun & Schatz, 2006; Orner, 2006).

Sociodemographic Factors

One of the few quantitative South African studies to assess parenting stress in caregivers (10% of whom were grandmothers) of HIV-positive children found that improved housing facilities, the presence of fewer adults in the household, and higher educational levels in the caregiver were associated with lower stress levels over a 1-year period (Potterton et al., 2007).

Multiple Roles

Caregivers were found to be shouldering the burden of managing multiple roles and responsibilities, such as caring for the ill, earning an income and overseeing the performance of household chores (Akintola, 2006; Ferreira et al., 2001; Makiwane et al., 2004; Orner, 2006; Schatz, 2007). It was found that seeing to the needs of others in the household in addition to that of the care-recipient increased caregiver's feelings of burden (Orner, 2006)

Stigma

Studies have also demonstrated that that societal sources of stress increased subjective caregiver burden. For instance, respondents reported that they had to cope with stigma and prejudice towards themselves and the care-recipient. It was also reported that the impact of societal stigma as well as the tasks of caregiving restricted their social lives even further thus fostering a sense of isolation and despair (Ferreira et al., 2001; Orner, 2006). The potential impact of stigma on families was highlighted in the study by Ferreira et al. (2001) which found that 50% of those surveyed concealed the presence of HIV/AIDS in their households.

Lack of Assistance with Caregiving Tasks

Furthermore, caregivers have reportedly engaged in their tasks with little or no external assistance. Ferreira et al. (2001) found that 75% of the caregivers surveyed in their study reported receiving no formal or informal assistance with caregiving tasks. In certain instances there was assistance, but this was directed at the persons with AIDS (PWA) and not the elderly caregiver. The Mpumalanga study lent further support to the finding that elderly caregivers lacked assistance. Of the caregivers surveyed, 43% reported needing assistance with caregiving for their grandchildren. Of these, 41% received no help at all, and 41% received help "sometimes" (Makiwane, Schneider, & Gopane, 2004). The reasons for the lack of support vary. With regard to formal support, the study by Orner (2006) found that caregivers' knowledge of support structures and how to access those structures was poor. A possible reason for the lack of informal assistance within the household is the gendered division of labour in African households (Akintola, 2006).

Impact on Caregivers' Health

Further, caregiving impacts negatively on the caregiver's health status. Caregivers fulfilled their responsibilities despite their own ailing health, and tended to under-report their illnesses (Akintola, 2006; Brodrick & Mafuya, 2005; Ferreira et al., 2001; Schatz, 2007).Caregiving also takes an emotional toll on caregivers. This was found to be associated with disciplinary problems in grandchildren and feelings of empathy and concern that grandmothers felt for the plight of their grandchildren who had been impacted by HIV/AIDS (Ferreira et al., 2001; Makiwane et al., 2004).

Despite all of these negative factors associated with caregiving, there was a sense of being committed to caregiving (either out of love, a sense of responsibility or resignation) (Ogunmefun & Schatz, 2006; Orner, 2006). Caregivers were able to identify ways in which

they attempted to cope with their difficulties (e.g., walking, praying, attending counselling), and appeared motivated to improve their situation (Ferreira et al., 2001; Orner, 2006). To the latter end, and consistent with the respondents in the earlier study (Ferreira et al., 2001), these respondents cited the need for business skills, caregiving skills, counselling and food as their most urgent needs.

The South African studies (e.g., Akintola, 2006; Brodrick & Mafuya, 2005; Ferreira et al., 2001; Makiwane et al., 2004; Orner, 2006; Ogunmefun & Schatz, 2006; Schatz, 2007) reviewed here, then, highlight that caregiving in the South African HIV/AIDS context occurs against a backdrop of poverty, lack of skills and support, and limited access to resources. The physical, financial and emotional consequences for caregivers are clear. The physically and emotionally taxing role of caregiving is left primarily to females, placing their physical and mental well-being at risk. Elderly caregivers, in particular, are at higher risk for contracting TB and HIV, and for developing depression and other emotional problems. The risk is greater if symptoms are not studied, reported and responded to, a fact that is especially important because some studies (e.g., Akintola, 2006) have found that female caregivers (perhaps because of the sense of duty that underlies the act of caregiving for family members) rarely report symptoms of physical or psychological stress or ill health.

While giving a useful, rich description of the lived experiences of caregivers within the context of deprivation and HIV/AIDS, the developing world studies do not account for the degree to which various stressors impact on caregiver burden. An understanding of whether the act of caring for the ill, or the lack of basic resources, or a combination of these various factors results in feelings of burden/stress in the caregiver, would be useful in guiding future research and interventions.

The current study therefore aims to fill that gap by quantitatively assessing the degree of burden experienced by grandmothers caring for their grandchildren in households that have been impacted by the HIV/AIDS epidemic. I further aim to ascertain, by means of statistical analysis, which (or which combination of) socio-demographic factors best predicts the level of burden that such grandmothers experience as a result of caregiving.

CHAPTER TWO: METHODOLOGY

Participants

A sample of 53 individuals participated in the study. All resided in the Western Cape townships of Khayelitsha (n = 40) and Gugulethu (n = 13). All participants were members of Grandmothers Against Poverty and AIDS (GAPA), a community-based non-governmental organisation. During the course of data collection two interviews were abandoned. In the first case, it emerged that the respondent had already participated in a pilot study for this research; in the second case, it emerged during the course of the interview that the respondent did not meet the study's selection criteria.

Selection criteria were that all the participants: (a) were members of GAPA, (b) were grandmothers, (c) were the primary caregivers of their grandchild/grandchildren, and (d) lived in a household that had been impacted by HIV/AIDS.

Sampling Procedure

Prospective participants were contacted via the GAPA member database. Initially, grandmothers were selected from the database using interval sampling. However, due to logistical constraints (such as difficulty contacting participants, participants' transport difficulties, a high rate of late arrival and irregular attendance at interviews), this method was abandoned in favour of convenience sampling. If expected interviewees did not arrive, grandmothers who were at the GAPA center on that day were invited to participate.

Representativeness of the Sample

Participants in the study were adult, female, Xhosa-speaking, and lived within two specific geographic localities in the Western Cape (Khayelitsha and Gugulethu). Therefore the sample surveyed in this study represents a specific sector of the South African population and cannot be generalised to the population as a whole. The limitations of the above is discussed later in this thesis.

The Research Site

Residents of Khayelitsha and Gugulethu were historically disadvantaged by South Africa's previous apartheid government policies. They continue to be amongst the neighborhoods in Cape Town with the poorest infrastructure, lowest household income and highest HIV/AIDS prevalence rate (Department of Social Development, 2007).

Khayelitsha is a township that was formed in 1984 as a direct result of the racially discriminatory housing policies of the apartheid government. It is located approximately 26km from the city of Cape Town's central business district and consists of both formal and informal settlements (Department of Social Development, 2007). The 2001 census data estimates that the population of Khayelitsha is 329 000 (Statistics South Africa, 2003).

Gugulethu is situated approximately 20km from the Cape Town CBD. Formed in 1958, it is one of the oldest townships in South Africa (Biggs, n.d.), and has an estimated total population of 80 277 (Statistics South Africa, 2003).

GAPA

GAPA was formed in response to a pilot project conducted by the University of Cape Town's Albertina and Walter Sisulu Institute of Ageing in Africa (IAA), in collaboration with community organisations.

The organisation provides support for grandmothers whose families have been impacted by the HIV/AIDS epidemic. GAPA has been based in Khayelitsha since 2001 and has branches in Gugulethu and in the Eastern Cape. Grandmothers who are over the age of 50 and whose families have been affected by AIDS (e.g., whose children have died of AIDS-related causes) are eligible for membership. Exceptions are sometimes made with regard to the minimum age required for membership. Recent research shows that the age range of GAPA members is 40-90 years, with the largest percentage of members (37%) between the ages of 50 and 59 (Brodrick & Mafuya, 2005).

GAPA attempts to empower its members by providing practical support and education to them. Weekly psychosocial support groups are facilitated by grandmothers who have been trained to do so. These groups consist of approximately 10 members each and are conducted at the homes of the group leaders. Three-day educational workshops, held monthly and accommodating approximately 30 members, are designed to cover topics such as nutrition, child care, and business skills. Monthly Indabas, open to all GAPA members, also cover various topics such as rape, crime and elder abuse. Furthermore, GAPA provides aftercare for deserving children who attend the local primary school. Two grandmothers provide supervision for the children and teach them skills such as beading.

GAPA is also a source of indirect financial support to its members. Members belong to business cooperatives through which they engage in income-generating projects. The organisation provides bursaries for children under the care of its members to attend the local crèche, equips members with skills to start their own businesses, and employs grandmothers to make craft items for sale at local businesses (Brodrick & Mafuya, 2005; GAPA, n.d.).

Questionnaire Selection and Development

Informal discussions regarding the development of the questionnaire(s) to be used in the current study were held with the founders of GAPA and with members of the organisation's board of directors. Additionally, I conducted a brief review of previous studies on caregiver burden, as well as of previous studies on the South African Xhosa-speaking population (Drennan, Levett, & Swartz, 1991; Smit, van den Berg, Bekker, Seedat, & Stein, 2006). Subsequent to these discussions and reviews, I decided that the questionnaire should strive to be, in equal measure, brief and culturally appropriate.

Many previous studies, across various cultures and populations, that aimed to assess the burden of caregiving, utilised standardised scales. I therefore decided to use a standardised scale, The Burden Interview (BI) (Zarit et al., 1980, 1985), to measure the degree of burden experienced by caregivers. Because this instrument is focused on the negative aspects of caregiving, I added open-ended questions to the end of the BI to allow for the respondents' expression of positive caregiving experiences.

Previous studies investigating the burden of caregiving requested demographic information (e.g., age, socio-economic status, living conditions) and information about activities of daily living from respondents (see, e.g., Kim et al., 2008; Kosmala & Kloszewska, 2004; Landry-Meyer et al., 2005). I therefore also decided to design a questionnaire that would gather data from participants on basic socio-demographic information and activities and tasks of daily living. The wording and categorisation of the questions were based on a study of previous questionnaires administered to similar South African population groups (Makiwane & Kwizera, 2006). Importantly, I added open-ended questions about the participants' care-giving experiences and their perceptions of GAPA to this socio-demographic questionnaire. The BI (including open-ended questions about positive care-giving experiences) is shown in Appendix A, and the socio-demographic questionnaire is shown in Appendix B.

Instrument Selection

As mentioned above, I used this standardised instrument to assess the subjective impact of caregiving on the respondents. The original version of the BI is a 29-item scale that was developed based on the clinical experiences of caregivers of elderly people with dementia (Zarit et al., 1980). The scale has been adapted into a 22-item version that was developed as a composite measure of caregiver burden in that it combines various aspects of caregivers' reactions to caregiving (Zarit et al., 1985). The latter version was used in the current study. Thus, respondents were presented with 22 statements, divided into five categories (health, finances, psychological well-being, social life, and relationships), that described their responses to caregiving. They were asked to rate their response to each item on a five-point Likert-type scale with categories ranging in frequency from "never" to "nearly always." A higher total score on the scale thus suggests a greater degree of burden.

The BI is most often administered in a self-report format. Numerous researchers have, however, found that the use of a self-report measure has limitations when used to evaluate psychological distress (e.g., Hunt, 2003). When faced with such measures, caregiver respondents may under-report their problems, either because of denial or because of a lack of awareness of the impact of caregiving on their well-being (Robinson & Austin, 1998, in Hunt, 2003). Hence, in the current study I used an interviewer to administer each questionnaire orally and individually, thus allowing the opportunity to detect avoidance and denial in participants and to gently probe where necessary.

I chose to use the BI because it satisfied the following guidelines for instrument selection in cross-cultural research (Flaherty, 1998, as cited by Smit et al., 2006), as outlined below.

1. The instrument has been used in other cultures. The BI is the most widely used instrument to assess burden in caregivers (Parks & Novielli, 2000), and has been adapted for use in many different cultures (see, e.g., Arai et al., 2007; Kim et al., 2006). While it has been previously used in South Africa on an English speaking population, to my knowledge it has not been used in the South African Xhosa-speaking population prior to this study.

2. The instrument has been developed to understand the construct under investigation. The BI, as noted above, was derived from clinical experiences and research findings, and was designed to assess the subjective burden of caregivers of dementia patients (Roach & Welch, 2000). The present study investigates the experiences of a population of grandmothers caring for their grandchildren, and it may therefore be

argued that the BI may not be an appropriate instrument for this purpose. However, the BI has been used to measure burden of care across various caregiving populations, such as caregivers of elderly people both with and without dementia (Kim et al., 2006), family caregivers of patients with schizophrenia (Magana et al., 2007), and female caregivers of family members with HIV/AIDS (Muthoni Kimemia, 2006). Furthermore, Bachner and O'Rourke (2007) found that the BI is reliable across populations of caregivers and care-recipients. Further, the instrument's developer did not reveal any concerns about the use of the scale as a measure of caregiver burden in grandparents caring for grandchildren in HIV/AIDS affected households (S. H. Zarit, personal communication, 9 January, 2007).

3. The instrument has known psychometric properties. A review of the psychometric properties of the BI by Kinsella et al. (1998) revealed a Cronbach's alpha of 0.91, indicating satisfactory internal consistency. The same paper described a satisfactory test-retest reliability of 0.71. Furthermore, these authors posit that the BI has adequate content validity due to the clinical and research base of the questionnaire. Evidence of construct validity is found in negative correlations between BI scores and morale, and in positive correlations between BI scores and hours spent giving care (Pratt, 1986, in Kinsella et al., 1998).

In summary, the BI was selected because it has been previously used in non-Western cultures, because it has been used across various populations of caregivers and care recipients, and because it has good psychometric properties.

Cross-Cultural Equivalence

Various steps, outlined below, were undertaken to ensure cross-cultural equivalence of the study.

Cross Cultural Adaptation of the Research Instruments

The Burden Interview. For the purposes of the present study, permission was obtained from the author of the scale for the adaptation, translation and use of the scale. Taken at face value, the original scale appeared easily comprehensible to a South African population; however, some changes were made prior to translation (See Appendix A).

Socio-demographic questionnaire. After creating a draft version of this questionnaire, I held informal discussions with GAPA board members, which included founding members

of the organisation as well as members of the Khayelitsha community, to discuss the appropriateness of the questionnaire and administrative procedures. Subsequent to these discussions, I changed the phrasing of certain questions. For example, in the draft version of the questionnaire participants had been asked to state their age. It was suggested that they instead be asked for their date of birth as that information would be well known to participants. If asked for their age, participants may have responded with "I don't know."

Translation. The Burden Interview has been successfully translated from the original English into many languages, including Japanese, French, German, Dutch, Spanish, Turkish, Swahili and Kikuyu, and subsequently used in many different countries (see, e.g., Arai et al., 1997; Bachner & O'Rourke, 2007; Magana et al., 2007; Muthoni Kimemia, 2006; Potgieter & Heyns, 2006). It has therefore clearly also been used cross-culturally. For the purposes of the current study it was necessary to translate the BI into Xhosa, the language spoken by the participants.

The techniques of back-translation and de-centering were utilised to ensure accurate translation from English to Xhosa. Back-translation is an effective technique in ensuring culturally equivalent instruments (Brislin, Lonner, & Thorndike, 1973). An experienced bilingual translator translated the English questionnaire into Xhosa. Utilising techniques outlined in the literature (e.g., Brislin et al, 1973) as a guideline, the questionnaire was then translated with the aid of a second bilingual translator back into English, and appropriate changes to the wording of the questionnaire were made. These changes were made orally due to logistical constraints. The researcher was present to clarify the intended aim of each item. As a further measure, the research assistant, a third bilingual individual, assisted the researcher in evaluating the quality of the translation by comparing each item on the English and Xhosa versions. The emphasis during the latter two stages was on achieving conceptual accuracy.

There was a general consensus amongst the translators and back translators that the translation was of acceptable quality. There was also, however, some disagreement on whether or not to use a formal, or informal and more frequently spoken, dialect of Xhosa. Drennan et al. (1991), in their study of the translation process in South Africa, found that amongst translators of Xhosa, there may be disagreement between urban and rural dialects. Specifically, in that study urban Xhosa speakers did not always appreciate the subtleties that rural Xhosa speakers used. In the current study, the use of a committee of translators and

piloting of the questionnaire with bilingual individuals may have been a useful approach (Brislin et al., 1973). However, time and financial constraints did not allow for these steps to be taken. Consultation with the project manager at GAPA, however, established that most GAPA members spoke the Eastern Cape dialect of Xhosa and it was therefore decided to utilise that dialect in presenting the questionnaire.

The Use of Likert-type Scales Cross-Culturally

Previous research with Xhosa-speaking subjects revealed that the translation into Xhosa of the categories of Likert-type scales, as found on the BI, is challenging (Smit et al., 2006). For example, in the present translation of the BI it was found that distinguishing between translated categories such as "rarely" and "sometimes" was difficult. Therefore, in addition to the literal translation of items on the Likert-type scale, numbers and incremental gradations of colour, indicating increasing frequency, were presented to respondents on laminated cards. The use of visual cues and numerical data in Likert-type scales has been found to be helpful in producing reliable data (Davies, 2005). I felt that the additional use of visual cues, especially with participants who may be illiterate, would be useful for the current research purposes.

Research Assistant

Brislin et al. (1973) stress the need for the researcher to understand the culture in which s/he is working and to vary his/her approach accordingly. This consideration was of prime concern when selecting the research assistant, who, I decided, should be of the same gender, racial and cultural group as the participants. She was comprehensively trained in the aims of the research and in the methods of administration of the questionnaires, and the intent behind each question was explained to her. These steps were taken in order to equip her to clarify potential misunderstandings during the interview. The assistant was also provided with an English copy of the questionnaire in order to assist her in making accurate clarifications.

Administrative Considerations

The GAPA board also advised that interviews be conducted during mid-morning, from 10am to 1pm, allowing participants sufficient time to arrive at the venue in the morning. They also strongly suggested that the interviews not encroach on lunch time.

Procedure

Ethics Approval

The Research Ethics Committee of the University of Cape Town's Department of Psychology provided approval for the study. Furthermore, the research team met with members of the board of GAPA and obtained permission to conduct the study using GAPA members as participants, and utilising GAPA premises for study interviews.

Introducing the Study to Prospective Participants

The researcher and research assistant attended one of GAPA's monthly Indabas. There, we introduced the aims of the research to a sizeable number of GAPA members. At that time, members were also given an opportunity to ask questions about the research.

Pilot Interviews

After this introductory session at the Indaba, pilot interviews were conducted with four GAPA members. Participants for the pilot interviews were selected using convenience sampling (i.e., those who lived closest to the interview venue were invited to attend). The pilot interviews were conducted by the research assistant, with the researcher present. The researcher's presence allowed for the detection and correction of any administrative errors.

In the course of the pilot interviews, we observed that the participants had no significant problems comprehending the questions, suggesting that the translation of the items had been adequate. Further, the research assistant was able to provide relevant context to the questions when needed.

After completion of these pilot interviews, and based on observations made during those sessions, changes were made to the interview schedule to allow for easier administration. For example, the pilot interviews indicated that there should be additional categories on questions such as, "What are the main household expenses?" The pilot interviews also alerted the researcher and research assistant to contradictions that might have emerged within the interview, and the need to detect and clarify these in the interview. For example, some pilot participants stated that their source of income was limited to their pension, but in response to a later question stated that a child support grant had been helpful in alleviating difficulties involved in caregiving. The researcher and research assistant also noted that on questions such as household composition, it was important to specify that the question referred to those who had resided in the household for at least 4 months of the past year, in keeping with the

definition outlined in the questionnaire of a previous study on a similar population group (Ferreira, 2004).

Data Collection

Prospective participants were contacted by the research assistant and/or the GAPA Project Manager, and mutually suitable meeting times at the GAPA centers in Khayelitsha and Guguletu were arranged. Study interviews were generally conducted on weekdays between 10am and 2pm.

Participants were interviewed individually in Xhosa by an experienced and bilingual (English and Xhosa) research assistant. The interview session began with a brief period of rapport building, after which participants completed the informed consent procedure. This procedure included a briefing on the aims of the research, reassurance about the confidentiality of their answers, and confirmation of their right to withdraw from the study at any time. A formal consent form (see Appendix C) was provided, and consent to the study procedures was indicated by either a signature or, in the case of participants who could not write, a cross.

After completion of these informed consent procedures, the formal interviewing process began. Data were collected using the questionnaires described above. The questionnaires were orally administered because, due to past political inequalities in South Africa, many within the African elderly population have low levels of education. It was therefore expected that some participants might have been illiterate, and it was decided that the questions would be read out loud to participants and that the answers would be recorded by the research assistant. This method of oral administration also provided an opportunity to clarify any misunderstandings regarding the questions. The duration of the interview was 45-75 minutes.

At the conclusion of the interviews, participants were reimbursed for transport costs; this financial compensation is consistent with the usual GAPA practice when participants are invited to attend workshops and meetings at the center. As a means of additional compensation, participants were given grocery vouchers to the value of R20.00.

Data Analysis

Quantitative Data

I decided to utilise data from the pilot study (4 interviews and questionnaires), along with data from the 53 participants interviewed, as described above, in the final analysis. This

utilisation is justified because the changes made to the questionnaire post-pilot were minor and did not compromise the utility of the data collected during those pilot interviews. Thus, a total of 57 participant interviews and questionnaires were available for analysis. Although a bigger sample size would obviously have yielded more statistical power, recruiting more participants was not possible due to logistical constraints.

All quantitative data were analysed using the Statistical Package for the Social Sciences (SPSS) version 16.0 (SPSS Incorporated, 2006). A multi-phased data analysis approach was used. First, I calculated descriptive statistics as a preliminary exploration of the data and to ensure that the data had been adequately cleaned. The descriptive statistical analysis also provided a comprehensive portrayal of the sample characteristics and the participants' responses to the socio-demographic questionnaire and the Burden Interview. Thus, frequencies and other relevant descriptive statistics (measures of spread and measures of central tendency) were obtained for both the dependent variable and the continuous independent variables. For the categorical variables, only the frequencies were calculated.

The results of this descriptive analysis, together with findings from the literature, were then used to identify variables that were the most likely predictors of caregiver burden. I then conducted a multiple regression analysis to determine which variables were the most significant predictors of BI-measured caregiver burden.

The processes involved in data entry and data cleaning, as well as the process of selecting the variables for entry into the regression model, are outlined in the Results chapter.

Qualitative Data

The research assistant textually recorded participants' responses to the six open-ended questions enquiring about caregiving experiences and their perceptions of GAPA's role in assisting them. While the recording bias of the research assistant must be considered (Ryan & Barnard, 2003), care was taken to record what had been said as accurately as possible. As a result, although the data capture the essence of what the participant said, they cannot be considered verbatim responses.

These data were analysed using principles of thematic analysis as a guide. Thematic analysis has been cited as a viable analytic technique for brief, non-verbatim responses (Braun & Clarke, 2006; Ryan & Barnard, 2003). The responses were thus analysed for recurring topics

as well as similarities and differences across the data set; from this analysis, I generated a set of meta-themes (Ryan & Bernard, 2003).

Ethical Considerations

Consent

Before enrolling a participant in the study, a statement was read to that individual, in her home language, outlining the purposes of the study, the fact that participation was voluntary, and of the right to refuse to participate or to withdraw without penalty at any time. Potential participants were informed that although the study might improve understanding of their circumstances, it was unlikely that they would experience any noticeable personal gains as a direct result of their participation

Confidentiality

All interviews were conducted in a private room on GAPA premises. Conducting the interview at GAPA was a potentially sensitive issue as some of the questions revolved around participants' perceptions of the organisation, while others asked about the HIV status of respondents and their families. Therefore, special care was taken to assure participants of the confidentiality of their responses. Before any questionnaires were administered, participants were informed that their names would not be used either during data entry or in any of the reports linked to the study.

The room in which interviews were held was also used for craft work tendered to GAPA by local businesses. As a result, the interviewer was sometimes forced to use the GAPA project manager's office or the pantry (which was in a private area, but without a door) for interviews. Despite these circumstances, the confidentiality of responses was always ensured.

Risk to Participants

The requirements of the present study did not place participants at any physical, social, or emotional risk. Respondents may have been considered to be a high-risk group due to their risk of HIV infection and their advanced age, but their membership in GAPA may have offset these potential vulnerabilities.

Incentives

The use of rewards, gifts or incentives in human science research has been subject to intense debate. Grant and Sugarman (2004) argue that the use of incentives is innocuous except in certain cases, such as when the participant is in a dependent relationship with the researcher, when the research is degrading or risky, or when the participant consents only if the incentive is high enough. The Department of Health's ethical guidelines for HIV research in South Africa (The National Department of Health, 2004) concur with the above and indicate that incentives should not be excessive so as to make the participant "an offer that they can not refuse" (The National Department of Health, 2004, Appendix A, p. 52).

As noted above, in the present study participants were given a voucher to the value of R20, to be used at a local supermarket. The amount was sufficient to cover the cost of three or four basic grocery items such as milk, sugar and tinned food. Vouchers were deemed to be practical because they allowed participants to purchase items of their choice, and because they were more convenient to distribute than cash or actual grocery items.

Feedback

Feedback to participants on the results of the study will be in the form of a short appropriately-worded report that will be presented to GAPA leadership, who will then distribute it to interested members.

CHAPTER THREE: RESULTS

Data Entry

Questionnaire data were entered into a Microsoft Access database. Some of the demographic questions were re-categorised during this phase to enable more meaningful analysis. For example, the socio-demographic questionnaire elicited information on the housing conditions of the participants. These questions covered four categories, including type of dwelling, access to water, access to toilet facilities, and access to electricity. Each of these categories was further sub-divided to indicate the quality of service received. During data entry, the answers to the four categories were re-coded into one category that indicated only whether the overall housing conditions were of a high, medium or low quality. I also decided to calculate and record the number of children younger than 6 years of age for whom the respondent was the primary caregiver. This decision was based on the observation that younger children require more care and assistance with tasks such as bathing and dressing.

For the question regarding how long the participant had been a member of GAPA, I had to utilise an estimated value. Participants in the study responded to the question by stating the year in which they had joined the organisation. However, some participants stated that they had joined GAPA during the current year, but did not specify in which month they had joined. It was later decided to determine the period that they had been at GAPA by utilising February (the month in which GAPA opens for the year) as the month in which they had joined GAPA. All responses to the above-mentioned question were then re-calculated as the number of months for which the participant had been a member of the organisation (instead of number of years). As we did not have access to the exact date on which they had joined the organisation, the value should be considered an estimate.

Answers to the open-ended questions were also coded and entered into the database. For example, the number of participants who reported positive experiences of caregiving, and the number of chronic illnesses reportedly experienced by the participant, were recorded.

Cleaning the Data

Missing Values

Examination of the data revealed a total of 15 missing values. Eleven of these were for the following variables: *Household characteristics: number of adults; Household characteristics: number of children; age of the youngest child under the participant's care;* and *age of the*

oldest child under the participant's care. These missing data may be accounted for by the participant's uncertainty over the correct response. The other four missing values were for the variable *Age of Participant*; these can be accounted for by interviewer error. The information on ages was, however, later obtained from the GAPA database.

As can be seen, the number of missing values was relatively small, and there was no systematic pattern to the missing data. I therefore decided to calculate the measures of central tendency (mean, median and mode) for the remaining affected variables. These were then plotted on histograms. The measure which most closely approximated the central score then replaced the missing scores. With regard to the ages of the children under care, examination of the description of the caregiving activities performed by the participant indicated whether or not the child was of a school-going age. Separate measures of central tendency were therefore calculated for school-going (72 months-204 months) and non-school-going (< 72 months) children, and the values were substituted accordingly.

Outliers

I constructed boxplots for all the continuous independent variables in order to detect outliers that may have excessively biased the measures of central tendency (Field, 2005). As shown in Figure 1, numerous statistical outliers were thus identified. I determined that these values were not due to data entry or other recording errors, but instead were characteristic of the population that I intended to sample. For example, given membership criteria for GAPA and given that exceptions are made to those criteria, statistical outliers for the *Age of Participant* variable were not unexpected. As a result, no outliers were deleted from the dataset to be used for the analysis.

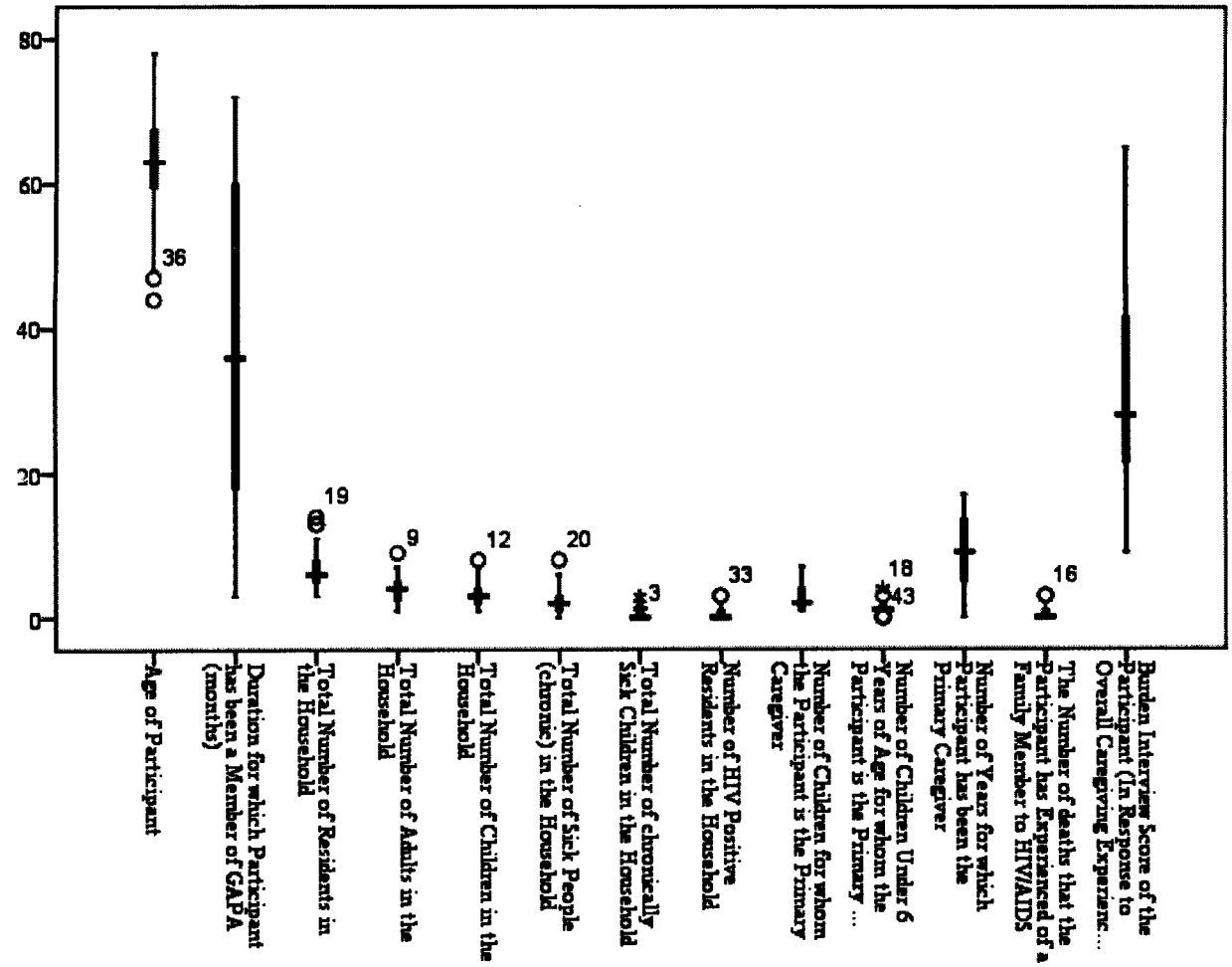

Figure 1. Boxplots of Continuous Variables

Results: Descriptive Statistics

As the study was both descriptive and exploratory, I will outline the socio-demographic characteristics of the sample by presenting frequency statistics for the categories of enquiry.

Caregiver Characteristics

The 57 respondents were all female; 44 (77.2%) of them resided in Khayelitsha, and the rest in Gugulethu. They ranged in age from 44-85 years old, with the majority (57.9%) falling into the 60-69-year-old range, and a further 24.6% being older than 70 years.

Duration of membership in GAPA ranged from 3-72 months, with most respondents (36.8%) having been members for at least 5 years; 19.4% had been members for 1 year or less. Support group membership (34 participants; 59.6%) was more common than co-op membership amongst those sampled.

Although a significant majority (91.2%) of the sample reported receiving some formal education, the level of education received varied. For instance, 45.6% reportedly received no more than a primary school level of education (i.e., 7 years or less), and 38.6% received junior-secondary education (9 years or less). Almost 20% of the sample (11 of the 57 respondents) reported being illiterate. With regard to employment status, 14% of the sample reported having some form of employment (e.g., being a cleaner or selling second-hand clothing at home).

Table 1 presents a more detailed description of the participants' demographic characteristics.

With regard to physical condition, ill-health was a common complaint amongst the participants, with 77.2% reporting at least one, and up to three, chronic illnesses. The response to this question was based on self-reports and therefore gives an indication of the subjective feeling of well-being amongst participants. As is shown in Table 2, hypertension and arthritis were the most common complaints; only 3.5% reported being HIV positive. Table 2 also presents the participants' self-reports of their most challenging daily household activities.

Table 1

Caregiver Characteristics: Demographics

Variable	Frequency	Percentage
Age (years)		
< 50	4	7.0
50-54	3	5.3
55-59	3	5.3
60-64	16	28.1
65-69	17	29.8
70-75	7	12.3
76-80	4	7.0
80+	3	5.3
GAPA membership duration (months)		
3	1	1.8
6	3	5.3
12	7	12.3
24	9	15.8
36	11	19.3
48	5	8.8
60	10	17.5
72	11	19.3
Highest education attained		
No schooling	5	8.8
< Std 5	26	45.6
Std 6-8	22	38.6
Std 9-10	2	3.5
> Std 10	2	3.5
Employment status		
Employed full-time	2	3.5
Employed part-time	4	7.0
Self-employed part-time	2	3.5
Unemployed	8	14.0
Pensioner	41	71.9

Table 2

Caregiver Characteristics: Physical Health and Activities

Variable	Frequency	Percentage
Chronic illnesses: Number		
0	13	22.8
1	14	24.6
2	26	45.6
3	4	7.0
Chronic illnesses: Types		
Arthritis	23	40.4
Hypertension	36	63.2
Asthma	4	7.0
HIV	2	3.5
Other (e.g., diabetes; heart problems; poor eyesight; depression)	13	22.8
None	13	22.8
Most challenging daily activities		
Cooking	45	78.9
Cleaning	52	91.2
Washing	32	56.1
Sewing	32	56.1
Child care	3	5.1
Food gardening	3	5.1

Household Characteristics

Household Composition

Household size varied from 3 to 14 members, with the most frequent range (25 of 57; 43.9%) being 4-6 members. In 25 cases, the number of adults per household was 4-6, with a range of 1-9 adults per household. A moderate number (9; 15.8%) of the households surveyed were "skipped generation" households, consisting only of one or two grandparents and co-resident grandchildren. In three generational households, the parents of the children were not always present. Most of the grandmothers surveyed (47; 82.5%) did not live with a spouse. The

questionnaire did not elicit further details on their marital status or the whereabouts of their spouse. When a spouse was present, he was invariably the head of the household (i.e., responsible for the final decisions made in the household), while in other cases the responding grandmother took on that role. Table 3 presents a more detailed view of the household composition data.

Table 3

Household Characteristics: Composition

Variable	Frequency	Percentage
Number of residents		
0-3	5	8.8
4-6	25	43.9
7-9	19	33.3
10-12	3	5.3
13-14	5	8.8
Number of adults		
0-3	27	47.4
4-6	25	43.9
7-9	5	8.8
Number of children (<18 years)		
1-2	30	52.7
3-4	22	38.6
5-6	2	3.5
7-8	2	3.5
9	1	1.8

Household Health Status

Although the number of chronically ill individuals in the surveyed households ranged from 0-8, the largest proportion of respondents (36 of 57; 63.2%) reported that 1-2 chronically ill individuals lived in their households (examples of reported illnesses include tuberculosis, HIV/AIDS, asthma, and mental illness). More detailed data on the overall health status of the household, including numbers of chronically ill children, are presented in Table 4.

Table 4 also shows the impact of HIV/AIDS on the surveyed households. For instance, 17.5% of respondents reported having one HIV-positive member in their household, and 7% reported having an HIV-positive child in their household. However, these statistics may be under-reported as the respondent was the only source of the information and, in many cases, was unaware of the HIV status of other (especially adult) residents of the household. Further, in many cases the respondent either reported that an HIV test had not been taken or that she did not know if a test had been done.

The impact of HIV/AIDS on households was not limited to the presence of infected co-residents. As Table 4 shows, 43.8% of households had lost at least one family member to the disease. Twenty-four respondents (42.1%) reported that they had nursed the HIV/AIDS-infected family member until their demise. Other possible impacts of HIV/AIDS, such as an infected non-resident family member or the death/illness of a family member's non-resident spouse to HIV/AIDS, were not directly measured by the questionnaire.

Household Socio-economic and Physical Status

As shown in Table 5, the majority of households surveyed were of a low income status, with most respondents (31 of 57; 54.4%) reporting that their monthly household income ranged between R1001 and R2000. Furthermore, most households reportedly relied primarily on the government old age pension and the child support grant as sources of income. Food (96.5%), clothing (77.2%), and electricity (66.7%) were cited by a majority of the respondents as the major household expenses.

With regard to the physical structure of the houses in which respondents lived, most households (45 of 57; 78.9%) were reportedly brick structures with electricity (94.7%), and indoor water (66.7%) and toilet (61.4%) facilities. Nonetheless, as is shown in Table 6, a notable number reported living in informal structures (21.1%) with outdoor water (33.3%) and toilet (38.6%) facilities.

Table 4

Household Characteristics: Health Status

Variable	Frequency	Percentage
Chronically sick residents		
0	5	8.8
1-2	36	63.2
3-4	13	22.8
5-6	2	3.6
7-8	1	1.8
Chronically sick children		
0	46	80.7
1	8	14.0
2	2	3.5
3	1	1.8
HIV-positive residents		
0	20	35.1
1	10	17.5
2	3	5.3
3	2	3.5
HIV-positive children[a]		
0	10	17.5
1	4	7.0
Deaths of a family member due to HIV/AIDS		
0	32	56.1
1	17	29.8
2	4	7.0
3	4	7.0

[a]Only 14 respondents could confirm the HIV status of the children in their household.

Table 5

Household Characteristics: Socio-economic Status

Variable	Frequency	Percentage
Estimated monthly household income		
<R500	0	0
R500 - R1000	16	28.1
R1001 - R2000	31	54.4
R2001 - R3000	9	15.8
R3001 - R4000	1	1.8
Primary sources of household income		
Salaries and wages	12	21.1
Old-age pension	45	78.9
Disability grant	4	7.0
Child Support grant	33	57.9
Foster Care grant	4	7.0
Gifts from family/friends	7	12.3
Money from self-employment	3	5.3
Primary household expenses		
Furniture	9	15.8
Clothing	44	77.2
Rent	7	12.3
Food	55	96.5
Medical	1	1.8
Loan	4	7.0
Electricity	38	66.7
Education	14	24.6

Table 6

Household Characteristics: Housing Conditions

Variable	Frequency	Percentage
Water supply: Inside	38	66.7
Water supply: On site	10	17.5
Water supply: Public tap	9	15.8
Electricity	54	94.7
Flush toilet (inside)	35	61.4
Flush toilet (in yard)	12	21.1
Bucket toilet (in yard)	10	17.5

Characteristics of Caregiving

Among respondents, primary caregiving duties had been assumed for as little as less than 1 year and for as long as 17 years. As displayed in Table 7, according to respondents' self-reports, the number of children under care ranged from one to seven, with approximately 77% of grandmothers reportedly caring for at least one child under the age of 6 years. Caregiving activities included seeing to the basic needs of the child such as bathing, dressing, and feeding (57.9%), as well as addressing complex needs, such as those related to medical care. Furthermore, the respondents had assumed responsibility for their grandchildren for various, and sometimes multiple, reasons. Financial difficulties of the parent or the parent living far away were cited by respondents as the primary reasons for becoming the grandchild's main caregiver of their grandchild. Finally, although most of the respondents (45 of 57; 78.9%) reportedly did not receive any assistance with caregiving, most (31 of 57; 54.4%) were able to reflect positively, or with some pride, on their experience of caregiving.

Table 8 shows frequency statistics for the BI administration to the current participants. Scores ranged from 9-65. Most respondents (29 of 57; 50.9%) reported experiencing mild to moderate burden.

Table 7

Caregiving Characteristics

Variable	Frequency	Percentage
Years for which participant has been primary caregiver		
<5	18	31.6
5-9	16	28.1
10-14	16	28.1
15-17	7	12.3
Children for whom participant is primary caregiver		
1	21	36.8
2	15	26.3
3	10	17.5
4	8	14.0
5	1	1.8
6	1	1.8
7	1	1.8
Children < 6 yrs for whom participant is primary caregiver		
0	13	22.8
1	32	56.1
2	8	14.0
3	2	3.5
4	2	3.5
Main caregiving activities performed by participant		
Bathing	40	70.2
Dressing	35	61.4
Feeding	33	57.9
Medical care	14	24.6
General supervision	25	43.9
Reason for becoming the primary caregiver		
Parent death	19	33.3
Parent illness	3	5.3
Parent living far away	21	36.8
Parent financial difficulties	25	43.9

Table 8

Burden Interview Global Score Frequency Data

Score Range	Category Descriptor	Frequency	Percentage
0-20	Little or no burden	14	24.6
21-40	Mild to moderate burden	29	50.9
41-60	Moderate to severe burden	13	22.8
61-68	Severe burden	1	1.8

Note. Category descriptions follow Zarit et al. (1985).

Regression-Based Statistical Analyses

Review of the descriptive statistics for the continuous independent variables (see Table 9) and of the frequencies of the categorical independent variables (see Tables 1-8) resulted in the selection of preliminary predictor variables. These were then further analysed to determine which variables would be entered into the final multiple regression model. This process entailed a number of steps, which will be outlined below.

Linear Regression

Linear regressions were conducted with each of the preliminary predictor variables and the outcome variable (the *BI Global Score*). For the purposes of these linear regressions, categorical variables with more than two categories (e.g., *Estimated Monthly Household Income*, *Number of Chronic Illnesses Reported by the Participant*) were dummy coded. The output was then analysed and predictor variables were considered for entry into the multiple regression model based on two criteria: those with significant *F*-values, and those that accounted most strongly for the variance in the model (higher R^2 values). Table 10 shows the list of the predictor variables thus selected for inclusion in the model. Appendix D presents a table depicting the values of the excluded variables.

One of the variables that would have otherwise been excluded based on the criterion of having a significant *F*-value, *GAPA membership duration,* was retained for theoretical reasons. More specific reasons for this choice will be explained in more detail in the next chapter.

Table 9

Descriptive Statistics for Continuous Independent Variables and Dependent Variables

Variable	Range	Mean	Mode	*SD*
Independent variables: Caregiver characteristics				
Age (years)	44-85	65.07	67	8.72
GAPA membership duration (months)	63-72	41.21	36	22.48
Support group membership duration (months)	0-72	22.42	0	24.36
Co-op group membership duration (months)	0-36	10.53	0	14.53
Independent variables: Household characteristics				
Residents	3-14	6.74	8	2.81
Adults	1-9	3.81	2	1.78
Children	1-9	2.82	2	1.74
Chronically sick residents	0-8	2.07	2	1.50
Chronically sick children	0-3	0.26	2	0.61
Residents tested for HIV	0-6	1.49	0	1.67
HIV-positive residents[a]	0-3	0.63	0	0.88
HIV-positive children[b]	0-1	0.29	0	0.47
Independent variables: Caregiving characteristics				
Children for whom participant is primary caregiver	1-7	2.30	1	1.39
Children < 6 years for whom participant is primary caregiver	0-4	1.09	1	0.91
Age of youngest child under participant's care (months)	2-168	52.63	24	38.48
Age of oldest child under participant's care (months)	2-420	110.56	24	71.69
Years for which participant has been primary caregiver	0-17	7.96	2	4.91
Dependent variable				
Burden Interview global score	9-65	30.11	22	13.56

Note: n = 75 unless otherwise stated. [a]*n = 35;* [b]*n = 14.*

Table 10
Univariate Regression of Predictor Variables

	R^2	Adj. R^2	F	p
Continuous variables				
Caregiver characteristics				
Age	0.06	0.04	3.41	0.070
GAPA membership duration	0.05	0.03	2.76	0.102
Household characteristics				
Residents	0.19	0.17	12.82	0.001*
Children	0.14	0.12	8.58	0.005*
Chronically sick residents	0.12	0.10	7.18	0.010*
Caregiving characteristics				
Children for whom participant is primary caregiver	0.21	0.20	14.63	0.000*
Children < 6 years for whom participant is primary caregiver	0.08	0.06	4.45	0.039*
Years for which participant has been primary caregiver	0.08	0.06	4.63	0.036*
Categorical variables				
Estimated monthly household income				
Dummy variable 1: R500-R1000	0.01	-0.01	0.33	0.567
Dummy variable 2: R1001-R2000	0.00	-0.02	0.16	0.695
Dummy variable 3: R2001-R3000	0.06	0.04	3.26	0.077
Assistance received by participant in caregiving	0.11	0.09	6.53	0.013*

*$p < .05$

Table 11

Normality Statistics for Continuous Predictor Variables and Dependent Variable

	Skewness			Kurtosis		
	Statistic	SE	*Z*	Statistic	SE	*Z*
Independent variables						
Caregiver characteristics						
Age	-0.21	.316	-0.677	0.28	.623	0.443
GAPA membership duration	-0.03	.316	-0.101	-1.32	.623	2.116
Household characteristics						
Residents	0.89	.316	2.810*	0.37	.623	0.589
Children	1.56	.316	4.930*	2.94	.623	4.724*
Chronically sick residents	1.49	.316	4.730*	3.69	.623	5.918*
Caregiving characteristics						
Children for whom participant is primary caregiver	1.18	.316	3.740*	1.43	.623	2.290
Children < 6 years for whom participant is primary caregiver	1.29	.316	4.073*	2.42	.623	3.866*
Years for which participant has been primary caregiver	0.17	.316	0.528	-1.28	.623	2.047
Dependent variable						
Burden Interview global score	0.45	.316	1.437	-.440	.623	-.706

Note. $n = 57$ for all variables.

*$p < .01$

Tests of Normality

In order to determine whether the scores on the eight chosen predictor variables with continuous data were normally distributed, tests of skewness and kurtosis were conducted. The values obtained were converted to *z*-scores. These normality statistics are presented in Table 11.

As is shown in Table 11, at a significance level of $p < .01$, I found that the five variables were not normally distributed. The distribution of these variables is presented in the histograms below.

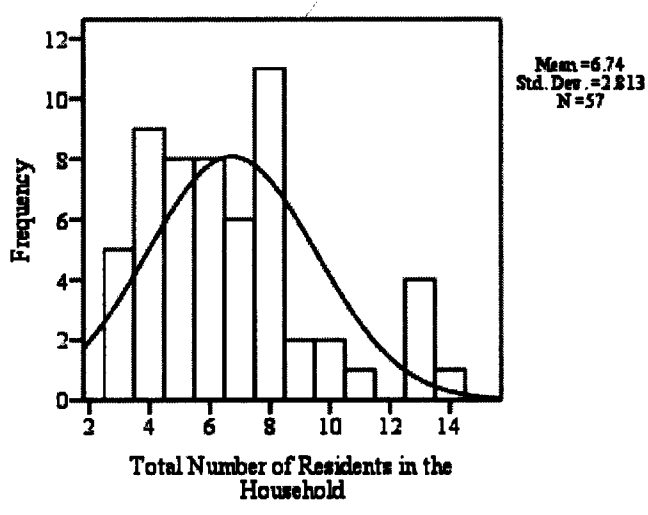

Figure 2. Histogram for the predictor variable *Household Characteristics: Residents*

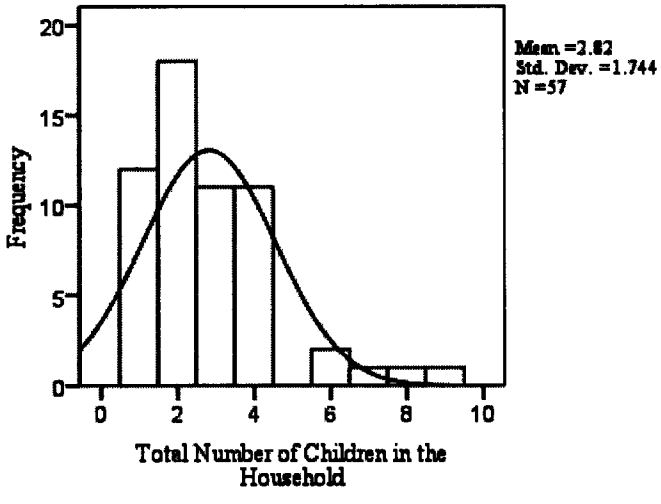

Figure 3. Histogram for the predictor variable *Household Characteristics: Children*

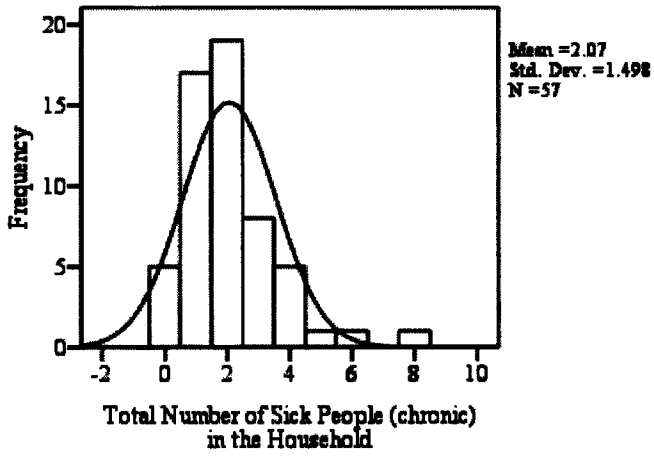

Figure 4. Histogram for the predictor variable *Household Characteristics: Chronically sick residents*

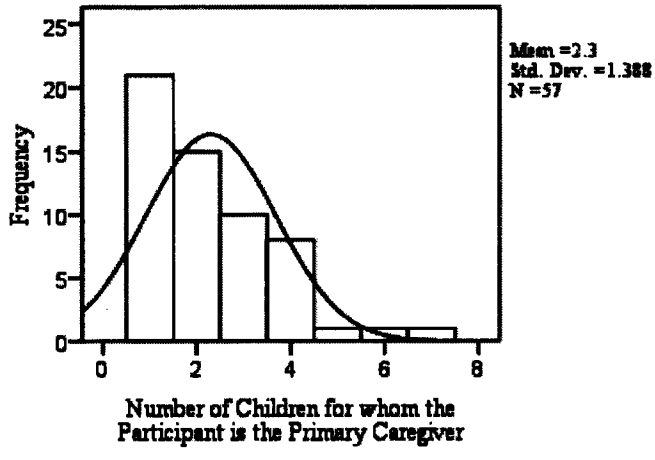

Figure 5. Histogram for the predictor variable *Caregiving Characteristics: Children for whom the participant is primary caregiver*

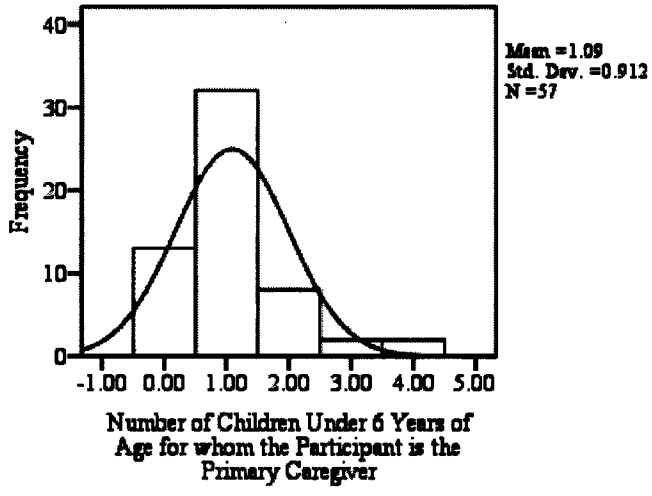

Figure 6. Histogram for the predictor variable *Caregiving Characteristics: Children < 6 years for whom participant is primary caregiver*

Correlation Matrices

I calculated bivariate correlations between each of the preliminary predictor variables and the outcome variable. This calculation was conducted to ensure that each of the predictor variables was correlated with the outcome variable but not strongly correlated (>.80) with other predictor variables (Field, 2005). This step allowed for the elimination of unsuitable variables from the final regression model. Decisions on which correlation test to use were based on whether the data was normally distributed or not. As a result, the non-parametric Spearman's Rho was used for the bivariate analysis of the continuous variables (see Table 12) and the point-biserial correlation was used for analysis of the dichotomous variable *Assistance received by the participant in caregiving* (see Table 13).

This data analytic step led to the conclusion that some of the *Household Characteristics* predictor variables were significantly correlated with each other. For instance, the variable *Children for whom participant is the primary caregiver* was strongly positively correlated with the number of *Children* in the household, $r = .83$, $p < .01$. Based on these data, I decided to drop the variable *Household Characteristics: Children.*

Table 12

Bivariate Correlation Matrix: Continuous Predictor Variables and Dependent Variable

Variable	1	2	3	4	5	6	7	8	9
Caregiver characteristics									
1. Age	----	.28*	-.25*	-.29*	.27*	-.11	-.13	.03	.19
2. GAPA membership duration		----	.19	.10**	.50**	.24*	-.02	.33**	.21
Household characteristics									
3. Residents			----	.70**	.31**	.65**	.41**	.27*	.37**
4. Children				----	.06	.83**	.32**	.48**	.38**
5. Chronically sick residents					----	.21	.04	.18	.30*
Caregiving characteristics									
6.Children for whom participant is primary caregiver						----	.33**	.60**	.45**
7.Children < 6 years for which participant is primary caregiver							----	-.23*	.24*
8. Years for which participant has been primary caregiver								----	.27*
Dependent variable									
9. BI Global Score									----

Note. $n = 57$ for each variable. Statistic presented is Spearman's Rho correlation coefficient.

*$p < .05$ (1-tailed); **$p < .01$ (1-tailed)

Table 13

Bivariate Correlation Matrix: Categorical Predictor Variable, Other Predictor Variables, and Dependent Variable

Variable	1
Categorical Variable	
1. Assistance received by participant in caregiving	**----**
Caregiver characteristics	
Age	**.20**
GAPA membership duration	**-.09**
Household characteristics	
Residents	**.05**
Adults	**-.02**
Children	**-.02**
Chronically sick residents	**-.17**
Chronically sick children	**-.08**
Estimated monthly household income	**-.06**
Caregiving characteristics	
Children for whom participant is primary caregiver	**.01**
Children < 6 years for which participant is primary caregiver	**.05**
Years for which participant has been primary caregiver	**.03**
Dependent variable	
BI Global Score	**.33****

Note. $n = 57$ for each variable. Statistic presented is the point-biserial correlation coefficient.
*$p < .05$ (1-tailed); **$p < .01$ (1-tailed)

Multiple Regression

In a multiple regression analyis, and using an alpha level of 0.05, eight predictors, and assuming a medium effect size (0.25), the current sample size ($n = 57$) yields a post-hoc statistical power of approximately .70 according to the G-power programme (Faul, Erdfelder, Lang, & Buchner, 2007). The predictor variables were entered into the model using the backward stepwise method of entry. I decided to use this method of entry because the study

was primarily exploratory in nature. Further, forward stepwise entry may have resulted in suppressor effects or may have increased the risk of a Type II error (Field, 2005).

The contribution of each predictor variable to the model was calculated and those that did not make a statistically significant contribution to the model were removed. The model was then re-estimated for the remaining predictors and the contribution of the remaining predictors was reassessed. This occurred in a stepwise fashion.

For the first model, as shown in Table 14, eight predictor variables were entered: Two *Caregiver Characteristics* variables (*Age* and *GAPA membership duration*), two *Household Characteristics* variable (*Residents* and *Chronically sick residents*), and four *Caregiving Characteristics* variables (*Assistance received by the participant in caregiving*; *Years participant has been primary caregiver*; *Children for whom participant is the primary caregiver*; *Children < 6 years for whom participant is the primary caregiver).* In subsequent steps (see Tables 15-19) the following predictors were removed in a stepwise fashion: *Years participant has been primary caregiver*; *GAPA membership duration*; *Residents*; *Children < 6 years for whom participant is the primary caregiver*; and *Age*.

As shown in Table 20, at each step of model building, the *F*-ratio improved significantly at $p < 0.001$ (from 5.024 for the first model to 12.165 for the sixth model), indicating an improvement in the prediction due to the model. The assumption that any errors in the regression were independent was shown to have been met, as indicated by a Durbin-Watson statistic of 1.814 (Field, 2005).

The final model included three predictor variables: *Children for whom participant is primary caregiver*; *Chronically sick residents;* and *Assistance received by the participant in caregiving*. Together these variables accounted for 40.8% of the variance in the BI global score. For every one standard deviation increase in the variable *Children for whom participant is primary caregiver*, there was an increase of .385 standard deviations in the Burden Interview score ($\beta = .385$; $p < .001$). This was followed by the variables *Assistance received by participant in caregiving* ($\beta = .375$; $p < .001$), and *Chronically sick residents* ($\beta = .321$; $p < .05$). The VIF values were less than 10 and the Tolerance statistics above 0.2 for all cases, indicating that there was no multi-collinearity in the data.

Finally, I analysed the residual statistics. This analysis identified two cases (3.5% of the sample) as having absolute standardised residual values outside of the limits of ± 2. However this percentage (3.5%) is well within what is expected for a sample of this size (Field, 2005). Further examination of these two cases revealed that the absolute standardised residual values were within the broader limits of ± 2.5. This analysis, then, indicates that the sample conforms to what would be expected of a fairly accurate model. Further examination of Cook's distance, Mahalanobi's distance, the Centered Leverage value and the Covariance ratio revealed that the values were within the expected range for the two identified cases. The table presented in Appendix E shows the diagnostic statistics for the two identified extreme cases.

Table 14

Results of multiple regression analysis: Model 1

Variable	*B*	*SE B*	β	*p*
Constant	**-9.06**	**13.16**	**----**	**0.49**
Caregiver characteristics				
Age	**0.31**	**0.19**	**.20**	**0.11**
GAPA membership duration	**-0.02**	**0.08**	**-.03**	**0.81**
Household characteristics				
Residents	**0.60**	**0.81**	**.12**	**0.47**
Chronically sick residents	**2.43**	**1.23**	**.27**	**0.06**
Caregiving characteristics				
Children for whom participant is primary caregiver	**2.59**	**1.94**	**.27**	**0.19**
Children < 6 years for which participant is primary caregiver	**2.15**	**2.01**	**.15**	**0.29**
Number of years for which participant has been primary caregiver	**0.07**	**0.43**	**.03**	**0.87**
Assistance received by participant in caregiving	**10.30**	**3.79**	**.31**	**0.01***

*$p < .05$

Table 15

Results of multiple regression analysis: Model 2

Variable	*B*	*SE B*	B	*p*
Constant	**-8.67**	**12.81**	**----**	**0.5(**
Caregiver characteristics				
Age	**0.30**	**0.19**	**.20**	**0.11**
GAPA membership duration	**-0.02**	**0.08**	**-.03**	**0.8**
Household characteristics				
Residents	**0.57**	**0.79**	**.12**	**0.47**
Chronically sick residents	**2.46**	**1.21**	**.27**	**0.05***
Caregiving characteristics				
Children for whom participant is primary caregiver	**2.80**	**1.44**	**.29**	**0.0(**
Children < 6 years for which participant is primary caregiver	**2.02**	**1.84**	**.14**	**0.2**
Assistance received by participant in caregiving	**10.37**	**3.73**	**.32**	**0.01***

*$p < .05$

Table 16

Results of multiple regression analysis: Model 3

Variable	*B*	*SE B*	B	*p*
Constant	**-8.54**	**12.67**	**----**	**0.5(**
Caregiver characteristics				
Age	**0.30**	**0.18**	**.19**	**0.11**
Household characteristics				
Residents	**0.57**	**0.78**	**.12**	**0.47**
Chronically sick residents	**2.37**	**1.13**	**.26**	**0.04***
Caregiving characteristics				
Children for whom participant is primary caregiver	**2.72**	**1.39**	**.28**	**0.0(**
Children < 6 years for which participant is primary caregiver	**2.06**	**1.81**	**.14**	**0.2(**
Assistance received by participant in caregiving	**10.43**	**3.68**	**.32**	**0.01***

*$p < .05$

Table 17

Results of multiple regression analysis: Model 4

Variable	*B*	*SE B*	B	*P*
Constant	**-4.69**	**11.48**	**----**	**0.68**
Caregiver characteristics				
Age	**0.26**	**0.17**	**.16**	**0.15**
Household characteristics				
Chronically sick residents	**2.71**	**1.02**	**.30**	**0.01***
Caregiving characteristics				
Children for whom participant is primary caregiver	**3.29**	**1.15**	**.34**	**0.01***
Children < 6 years for which participant is primary caregiver	**2.46**	**1.72**	**.17**	**0.16**
Assistance received by participant in caregiving	**10.94**	**3.60**	**.33**	**< 0.01****

*$p < .05$; **$p < .01$

Table 18

Results of multiple regression analysis: Model 5

Variable	*B*	*SE B*	B	*P*
Constant	**-1.53**	**11.37**	**----**	**0.89**
Caregiver characteristics				
Age	**0.23**	**0.17**	**.15**	**0.19**
Household characteristics				
Chronically sick residents	**2.54**	**1.03**	**.28**	**0.02***
Caregiving characteristics				
Children for whom participant is primary caregiver	**3.96**	**1.06**	**.41**	**0.00****
Assistance received by participant in caregiving	**11.15**	**3.63**	**.34**	**0.00****

*$p < .05$; **$p < .01$

Table 19

Results of multiple regression analysis: Model 6 (Final model)

Variable	*B*	*SE B*	B	*P*
Constant	**12.84**	**3.30**	**----**	**0.00**
Household characteristics				
Chronically sick residents	**2.91**	**0.99**	**.32**	**0.01***
Caregiving characteristics				
Children for whom participant is primary caregiver	**3.76**	**1.06**	**.39**	**< 0.01****
Assistance received by participant in caregiving	**12.37**	**3.54**	**.38**	**< 0.01****

*$p < .05$; **$p < .01$

Table 20

Multiple regression analysis: Summary of models

	Model Summary			ANOVA	
Model	R^2	Adjusted R^2	*P*	*F*	*p*
1	.46	.37	0.00**	5.02	< 0.01
2	.46	.38	0.87	5.85	< 0.01
3	.46	.39	0.83	6.95	< 0.01
4	.45	.40	0.47	8.31	< 0.01
5	.43	.38	0.16	9.69	< 0.01
6	.41	.37	0.19	12.17	< 0.01

Qualitative Analysis of Open-Ended Questions

The open-ended questions allowed participants to express their views on certain aspects of caregiving without the imposition of pre-defined categories. The data present in those responses, it was found, added to the quantitative data and potentially offered new areas for exploration in future research.

Data from the following two open-ended questions, both relating to the participants' experience of GAPA, could be categorised very simply because responses did not vary much across the sample:

1. Has GAPA equipped you with skills that you now use to earn an income?
2. How else has GAPA helped you to cope better with caring for your grandchild/grandchildren?

Data from the other four open-ended questions, all of which looked broadly at the experiences of caregiving and which are listed below, lent themselves more to analysis utilising the principles of thematic analysis as a guideline (Braun & Clarke, 2006; Ryan & Bernard, 2003):

3. What are the greatest problems that you experience in caring for your grandchild?
4. What has been of help to you in caring for your grandchild?
5. Is there anything else that you would like to say about your experiences of caring for your grandchild?
6. Are there any positive aspects to caring for your grandchild?

Thus, I will first outline the aspects of GAPA that participants suggested, in their responses to the first two questions, were beneficial to them. I will then present meta-themes that emerged, in their responses to the final four questions, regarding their experiences of caregiving. The number of participants that gave each response is indicated in brackets.

Experiences of GAPA

Fifty-one participants listed sewing (including handicraft, such as beadwork, crochet, and knitting) and five listed food gardening, as important skills that they had learned through GAPA and were using to supplement their household income. An overwhelming majority of respondents (40) found the monthly Indabas and educational workshops to be a useful source of information with regard to childcare. The Indabas were valued as an opportunity to share experiences with others. Discussion areas within Indabas and educational workshops that were listed as being helpful and informative were HIV/AIDS (42), nutrition (5), childcare (including discipline and listening skills; 12), and Business skills (7). Three respondents also noted that they found the support groups helpful. Four respondents cited material aid from GAPA (e.g., clothing for their children, payment of crèche fees) as aids to coping with childcare.

Experiences of Caregiving

Analysis of the data indicated that the participants experienced difficulties in caregiving as a function of characteristics of both the child and the caregiver. Some caregivers expressed difficulty in managing the emotional burdens of being a caregiver, such as a sense of responsibility and concern for the person under their care. Nonetheless there emerged, in some cases, a sense of pride in their contribution as caregivers, and an ability to reflect on the positive aspects of care. I will outline these areas under the following meta-themes: the physical and emotional burden of care; caregiver and child characteristics that contribute to caregiver burden; positive aspects of caregiving; and sources of assistance in caregiving.

The physical and emotional burden of care. I. Increased responsibility. Caregiving reportedly entailed increased and multiple responsibilities for the participants in the study. There were reports of struggling with the increased responsibility of supervising homework (2), accompanying children to and from crèche (2), taking the children for clinic visits (7), and waking at night or early in the morning to see to the needs of the children (e.g. to prepare them for school or crèche; 4). Additionally, three respondents reported that overseeing daily chores was taxing. A sizable minority of caregivers (12) also noted that they undertook the difficult responsibility for meeting the financial needs of their grandchildren (i.e., they had to cover the costs of medical care, education, and clothing).

The physical and emotional burden of care. II. Concern for the well-being of the child. Many of the grandmothers demonstrated concern for the current and future well-being of their grandchildren. Their concern covered various aspects of the child's physical and emotional welfare. For example, three participants reported being concerned for the safety of their grandchildren, with rape and HIV being mentioned as specific risks. Other concerns included that of the physical well-being of the child (e.g., immunisation and cleanliness; 7), and the need for good nutrition (11). The importance of securing an education for their grandchildren was also highlighted by four participants. With regard to emotional burdens, four participants felt that the emotional needs of their grandchildren were important. Talking to the children, listening to them and taking care they should not feel different or miss their parent/s excessively were mentioned as specific examples in this case.

The physical and emotional burden of care. III. Personal sacrifices. Eight of the participants gave responses that showed a tendency to place the needs of others in the family, especially

the care-recipients, before their own. Some of the caregivers reported that they were, in fact, unable to care for themselves and often put the child's needs first; one said she had to fulfil her responsibilities even if she was unwell. Two caregivers reported that they felt restricted in conducting their own activities as a result of caregiving.

Child characteristics as a contributor to caregiver burden. I. The age of the child. Younger children reportedly had "more energy," were more active and wanted to play with their caregivers. This presented a problem to 12 of the grandmothers, who reported that they often did not have the energy to play with the children. Further, they reported that they sometimes had to wake at night in order to see to the needs of the children. This was perhaps more common with younger children who sometimes required assistance in, for example, going to the toilet at night.

Child characteristics as a contributor to caregiver burden. II. The health status of the child. Four respondents noted that some of the children under their care suffered from chronic illnesses such as HIV, tuberculosis, asthma, and "mental illness." This increased both the demands of care within the home and the need for increased clinic visits.

Child characteristics as a contributor to caregiver burden. III. Emotional and behavioural difficulties. Three participants reported that the children under their care experienced distress over the demise of their parents. Others (14) reported disciplinary problems as a result of behavioural difficulties in the children. These difficulties were manifested in, for example, staying out late, refusing to go to school, or neglecting to assist with household chores. Finally, 10 participants reported that meeting the material demands of some of the children under their care was a stressor.

Caregiver characteristics as a contributor to caregiver burden. I. The health status of the caregiver. The health status of the caregiver reportedly impacted on the ease with which they fulfilled child-care responsibilities. Fourteen caregivers reported that, as a result of their age and deteriorating health, they often did not have the energy to fulfill all the needs of the child, such as playing with him/her or waking at night to see to his/her needs.

Positive aspects of caregiving. I. Pride in the caregiver role. In several responses participants showed evidence of pride over their contributions to the upbringing of their grandchildren.

For example, one grandmother spoke of how she had taught her grandchildren to walk and talk; eight others mentioned that they always made certain that the children were "clean and fed," and two noted with satisfaction that the children's religious needs were met . Responsiveness to the emotional needs of the children was also mentioned as a positive aspect, with some caregivers (4) emphasising that they communicated with the children, listened to their problems and treated them like their own. Fifteen others spoke of their love for their grandchildren, and of their desire to provide the best for them and to make them happy.

Positive aspects of caregiving. II. Benefits of caregiving. In a few cases, caregiving for grandchildren was seen by some respondents as a source of companionship (1); joy (2); appreciation (2); a means of improving family relationships (1); and a source of assistance in the household (2).

Sources of assistance in caregiving. Financial and material assistance were cited by many respondents as a means of assistance in caregiving. The child support grant (15); payment of crèche fees by GAPA (14); financial aid from family (6); and the government old-age pension (4) were the main sources of financial aid. After-care facilities (2) and family assistance with chores and caregiving (4) also provided relief.

CHAPTER FOUR: DISCUSSION

The primary aim of this study was to assess the impact of caregiving on grandmothers caring for their grandchildren in households that have been impacted by the HIV/AIDS epidemic. Another aim was to ascertain, by means of statistical analysis, which (or which combination) of the socio-demographic factors investigated in the study best predicted the level of burden that the grandmothers reported experiencing as a result of caregiving.

Descriptive Statistics: Summary and Discussion

Previous studies on the elderly in South Africa (e.g., Makiwane & Kwizera, 2006; Mba, 2005) and studies on elder caregivers in the developed world (e.g., Hayslip & Kaminski, 2005) have demonstrated that the elderly, and specifically elderly caregivers, are not a homogeneous group. The sample in the current study was therefore perhaps less heterogeneous than those in other studies, but this was by design: They represented a specific stratum of the population, and data generated by this study are not necessarily meant to generalise beyond older African females who have taken on caregiving roles due to the impact on HIV/AIDS on their families. More specifically, the sample in this study consisted entirely of females (mean age 65 years), all of whom were grandmothers from low socio-economic backgrounds and with fewer than 7 years of formal education.

Current findings on the socio-economic circumstances of the sample are not dissimilar to those of other studies on the elderly African population in other parts of South Africa (Hayslip & Kaminski, 2005; Makiwane et al., 2004; May, 2003; Mba, 2005; Møller & Ferreira, 2003; Noumbissi & Zuberi, 2001). More specifically, these previous studies suggested that whereas older White citizens of South Africa tended to live in nuclear families, alone, or in institutions, African, Asian and Coloured elderly were more likely to live in extended households. In the present study, almost 16% of the respondents were members of skipped-generation households (featuring only one or two grandparents and co-resident grandchildren), and the majority of the households were three generational. Furthermore, several previous studies suggested that African households were mostly poor (the elderly African population in South Africa is the most disadvantaged of all racial groups, given the history of apartheid and other past inequalities) and female-headed (May, 2003; Mba, 2005; Noumbissi & Zuberi, 2001). This exact pattern was present in the households surveyed in the current study: Monthly household income was mainly between R1000 and

R2000, and although most participants reported living in formal dwellings with basic amenities, a notable number lived in informal structures with outdoor water and toilet facilities.

Furthermore, most of the grandmothers were the heads of their households, without a co-habiting spouse. Again consistent with previous studies and with the general gendered division of roles in traditional African society, when a male spouse was present, he assumed the role of the head of the household (Mba, 2005).

Further with regard to socioeconomic circumstances of the current sample, for most participants the government old-age pension was the main source of household income. The contribution of the old-age pension to total household income and its use by multiple members of the household has been found, by past studies, to be greater in African households. For instance, in a study comparing African and Coloured households, it was found that the Coloured elderly were more likely to be able to use their pension income on themselves (Møller & Ferreira, 2003). This trend of pension-sharing in African households has an impact on the living arrangements of the elderly, primarily because it attracts economically dependent relatives to their household (May, 2003). The current study, which found that most households were multi-generational with an average of seven members per household, confirmed this trend.

Some authors, such as May (2003), have argued that this attraction of economically dependent relatives may have positive effects in that it might improve both the social integration of the elderly and their chances of being helped when they are in need. In the context of the HIV/AIDS epidemic, however, a counter-argument might be that financially dependent family members may also suffer from illnesses due to the virus, and that their presence in the household might therefore be an additional source of stress (e.g., as a result of increased medical costs and increased caregiving demands) rather than a source of help to the elderly provider. To bolster this latter argument, most respondents in the current study reported having at least one chronically ill family member within the household, and most households reported being directly impacted by HIV, either through the death or the current illness of a family member.

The dire socioeconomic circumstances of the participants in the current study also affected their health status. The high rate of self-reported chronic illnesses (most participants reported experiencing at least one chronic illness, such as asthma, hypertension, or arthritis) may be mistakenly attributed to a feature of normal ageing. However, numerous previous studies (e.g., Smyer & Qualls, 1999) have shown that the manner in which one ages is a function of current and past socio-economic factors, physical and mental health, and functional abilities. More specifically and in support of the above statement, it has been found that lower income levels were significantly associated with poorer self-reported health in the African elderly in Soweto (Gilbert & Soskolne, 2003). May (2003) found that elderly African urban women were more prone to illness than were white males or white females, and Ferreira, Møller, Prinsloo, & Gillis (1992) reported that older Africans experienced worse health than any other racial group in South Africa. The current data therefore lend some support to the assertion that older African females from low socio-economic backgrounds are more prone than are their more privileged counterparts to self-report chronic illness.

The Burden of Caregiving

Although a small number of participants stated that they derived benefits (such as assistance, companionship, and appreciation) from the caregiving situation, responses to the current study's open-ended questions generally indicated that caregiving has a negative emotional and physical impact on the caregiver (e.g., it is associated with increased responsibility, personal sacrifices and concern for grandchildren). Caregiver burden, on the open-ended questions, was demonstrated to be a function of characteristics of the caregiver (e.g., age and health status) and care recipient (e.g., age, health status and behavioural or emotional difficulties).

Given the context of socio-economic deprivation, the high number of dependents in the households surveyed, and the general tenor of responses to the open-ended questions, one might have expected that the BI global score would be quite high (i.e., would indicate a significant caregiving burden). This expectation was not met, however: The degree of burden reportedly experienced by the participants as a result of caregiving was primarily in the *mild to moderate* range on the BI. Approximately 25% of those surveyed reported *moderate to severe* burden, a further 25% reported *little or no burden* and only 2% of subjects reported experiencing *severe burden.*

Given the unexpectedness of this finding, it is worthwhile exploring it in further detail. A survey of relevant literature revealed three possible reasons for the trend. The first is a sense of duty amongst caregivers that may mediate the experience of burden; the second, socio-cultural norms regarding the gender-based division of roles; and the third, access to social support. Each will be outlined in further detail below.

In a large-scale study of multiple secondary data sources on older adults in South Africa, it was reported that participants, while experiencing frustration at the neglect of their own needs, also felt a "sense of purpose," "pleasure and self-esteem" (May, 2003, p. 20) in caring for their family through pension-sharing. A study in Agincourt, South Africa, found a similar sense of duty amongst elderly female caregivers (Schatz, 2007). Some participants' responses to the open-ended questions in the current study concurred with the above: they expressed a sense of pride in their role as caregiver to their grandchildren, while at the same time verbalising the toll it took on them both physically and emotionally. Therefore, one might conclude that, for the participants in this study, although caregiving is stressful, it provides them with a purpose and with a way of contributing to their families. Thus, this factor may serve as a mediator between the objective tasks of caregiving and the subjective perception of burden.

With regard to socio-cultural norms regarding gender-based division of roles as mediating factors, a study in the United States revealed that grandparent caregivers tended to under-report negative health outcomes of caregiving, and to put the needs of others above their own (Joslin & Harrison, 1998). A Kenyan study on female caregivers reported a similar outcome (Muthoni Kimemia, 2006). Therefore, it is possible that the grandmothers surveyed here tended to under-report their experience of burden as a result of socio-cultural norms regarding the importance of the family and the role of women as caregivers within the family unit.

Finally, and perhaps most importantly, with regard to access to social support as a mediating factor, all the women surveyed in this study were members of an organisation that provides regular emotional support and means of economic empowerment to affected grandmothers. Because of their GAPA membership, the grandmothers in the current study may have lower than expected scores on the BI.

Although I have no direct means of comparing elderly caregivers without such support to the grandmothers in this study, indirect comparisons with cohorts from other, independent, studies are consistent in arguing for the positive impact of social support. For instance, in the study in Mpumalanga of older caregivers of children under 18 years of age, participants were asked to rate the overall level of difficulty that they experienced with caregiving. They were asked to select from five responses, ranging from *none* to *mild*, *moderate*, *severe* and *extreme*. Two-thirds of those surveyed selected *moderate* or *severe* difficulty. Significantly, the participants in that study were not receiving any known form of regular social support (Makiwane et al., 2004). Compared to the current study, then, the Mpumalanga study revealed a higher level of burden amongst caregivers who were not accessing formal social support. This comparison is telling, although grounds for criticism of the utility of such a comparison do exist: a standardised scale was not used in the Mpumalanga study, and participants' responses were based on a single rating and purely on their subjective intuitive assessment of burdens of caregiving.

Multiple Regression Analysis: Summary and Discussion

Multiple regression modeling revealed that three factors were most predictive of the level of burden experienced by the caregivers in this study: the number of children for whom the participant was the primary caregiver, the total number of chronically sick individuals in the participant's household, and whether or not the participant received any assistance in caregiving. I will discuss each of these factors in detail, but will first discuss important decisions that were made regarding the inclusion of certain variables into the regression model.

Because the current study was exploratory in nature, consideration of which variables to utilise in the multiple regression analysis was based primarily on statistical considerations. However, even though two of the variables did not meet the statistical criteria for inclusion (as outlined in the Results section), they were considered for inclusion due to their theoretical significance.

The first of those variables, estimated monthly household income, was considered for entry into the model based on purely theoretical reasons, but was eventually excluded due to reasons outlined below. Consideration for the inclusion of the variable was based on various studies which cited poverty as a major contributor to caregiver stress in the elderly (Ferreira

et al., 2001; Landry-Meyer et al., 2005; Linsk & Mason, 2004; Makiwane et al., 2004; Mills et al., 2005; World Health Organisation, 2002). However, upon further examination of the current data, it appeared that poverty was a significant part of the lives of all those surveyed, and so household income would not have been a useful predictor of burden. Otherwise stated, any differences in income between households would not have been substantial enough to impact on the degree of burden, given that all households were categorised as falling toward the lower end of the socio-economic spectrum. Furthermore, because expenses may have differed between households (depending on, for example, the level of medical care required, or the number of residents) a more useful measure may have been the net income of household. The currently administered questionnaire did not, however, elicit information about the value of household expenses. I therefore eventually decided not to include household income as a predictor variable in the regression model.

The second variable considered for inclusion due to its theoretical significance was the length of time the participant had been a member of GAPA. As noted above, this variable did not meet the statistical criteria for inclusion, but remained under consideration because of the importance attached to social support by empirical studies in elderly caregiver literature. Previous studies have indicated that the absence of social support is common amongst grandparent caregivers (Dowdell, 2004; Ferreira et al., 2001; Hayslip & Kaminski, 2005; Joslin & Harrison, 1998; Landry-Meyer et al., 2005; Mills et al., 2005; World Health Organisation, 2002), and have further indicated that this absence may be strongly associated with the experience of caregiver stress.

Given these previous findings, I was interested in investigating whether the length of membership at GAPA (a source of social support) would predict the level of caregiver burden. This decision to further investigate this relationship was supported by analysis of participants' responses to the open-ended questions, which indicated that that GAPA indeed was a source of education, skills and psychosocial support. I therefore expected that those who had been GAPA members for a longer time would experience a lower level of caregiver burden.

The data did not, however, match this expectation: duration of GAPA membership was not a significant predictor of caregiver burden. The reasons for this lack of association may include that fact that joining GAPA could have had an immediate impact in decreasing the subjective

feeling of burden. In other words, it is possible that the expectation of being helped has an immediate and powerful impact on the individual's perception of their ability to cope (Shapiro & Taylor, 2002). Membership of the organisation over time (which ranged from 3 to 72 months) may have even further decreased both subjective and objective burden, but not to a degree that had a noticeable impact on the BI score.

The regression model found three variables to be significant predictors of caregiver burden in the studied population. I will discuss these in turn below.

Significant Predictor Variable 1: Number of children for whom the participant is the primary caregiver

It stands to reason that the greater the number of children under care, the greater the objective burden on the caregiver. It is also likely that having a greater number of children to care for may be more overwhelming for the caregiver, which may in turn result in increased burden. Further, multiple children in a resource-limited household could lead to greater competition, rivalry and dispute amongst the children, resulting in increased stress for the caregiver. While the questionnaire did not quantitatively measure the presence of behavioural problems in the children under care, past research has indicated that it is a significant predictor of burden (Bowers & Myers, 1999).

Significant Predictor Variable 2: Total number of sick people in the household

The measurement of this variable was based on subjective reports and included the respondent, as well as both adult and child residents of the household. While the efficacy of utilising subjective reports as a measure of health may be questioned, a recent study found that subjective measures (in addition to being time- and cost-effective) were as predictive of outcomes as objective measures of health (Kuhn, Rahman, & Menken, 2006).

Illnesses reported varied from HIV/AIDS through tuberculosis to asthma. Some of the illnesses reported (e.g., tuberculosis) have been linked in the literature to a positive HIV status (Mukadi, Maher, & Harries, 2001; Sonnenberg et al., 2005), although this link was not explicitly stated by all respondents. Four possible explanations for the significance of this predictor variable are outlined below.

Firstly, past research has demonstrated that the caregiver's own ill health is a predictor of increased burden (Bowers & Myers, 1999; Landry-Meyer et al., 2005). As indicated earlier in this section, ill health is not necessarily a feature of ageing, and may be present due to current or chronic past stress. Ill health in the caregiver may therefore, in part, account for the fact that this variable significantly predicts the level of caregiver burden. Secondly, it may also be argued that as the health status of the household declines, there is greater financial stress because of increased medical costs. Thirdly, a decline in the health status of residents would be likely to increase the stress on either the healthier members of the household, or on those in positions of responsibility. These members may then shoulder a greater responsibility for generating income and giving care. Fourthly, ill family members, who face a loss in earning capacity, may migrate to a home with a consistent income source, such as an old-age pension, resulting in increased household size and a greater burden on already over-stretched resources (Merli & Palloni, 2006; Møller & Devey, 1995; Møller & Devey, 2003).

Significant Predictor Variable 3: Assistance received by the participant in caregiving

The fact that this variable was a significant predictor of burden in the study population is an interesting, unexpected result and at first glance appears to be counter-intuitive: One would expect the presence of assistance to decrease the experience of burden. However, it is important to bear in mind that association does not indicate causation (Field, 2005). One plausible explanation is that caregivers who have higher degrees of stress are more likely to require assistance, and are perhaps more likely to insist to family members that they assist with caregiving.

Secondly, it is also possible that those who request and receive assistance do so because they are more aware of, and are better able to verbalise, their difficulty in coping. This quality may also predispose them to report their experience of caregiving in more realistic terms, resulting in a higher BI score.

A third possibility is that caregivers may offer remuneration for assistance received, which may then increase financial burden. This information was not elicited by the questionnaire, so it is unclear if this was the case in the current study.

General Summary and Conclusion

This study demonstrated that, in two Western Cape townships, elderly African females provide care to orphans and vulnerable children (OVCs) within a context of poverty, HIV/AIDS, chronic illness, multi-generational households, and socio-cultural norms that define gender-based roles. These circumstances are arguably a function of broader macro-level trends such as job scarcity (which leads to migration and shifting family structures); population ageing as a result of the HIV/AIDS pandemic (which results in a preponderance of households headed by elderly females); and the residual effects of apartheid policy.

At the micro- and meso-levels, the grandmothers surveyed here were recipients of formal social support through GAPA, an organisation that provided emotional support and economic empowerment. Within this context, caregivers feel some sense of pride in their roles as caregivers. Nonetheless, the experience of caregiving is one that is commonly described as emotionally and physically exhausting. According to qualitative analysis, the negative impa of caregiving on personal well-being may be exacerbated by individual characteristics of both the caregiver and the care-recipient (e.g., age and health status of the caregiver and care-recipient, as well as behavioural difficulties in the care-recipient). Chronic illness and financial difficulty (e.g., dependence on the government old-age pension as the primary source of regular income) both tended to increase the level of burden on the caregivers, as reported qualitatively.

Three factors were found to be statistically important predictors of burden: the number of children for whom the participant was the primary caregiver; the number of chronically ill people in the household; and assistance received with caregiving responsibilities. The latter finding probably implies that those who are the most stressed are most likely to require assistance with care.

This study should be considered a preliminary one on which future research may be based. The current findings will help increase awareness and understanding of the contributions and challenges of the elderly, and ideally result in policy changes that are responsive to their unique circumstances.

Limitations of the Study and Recommendations for Future Research

The first potential limitation of the current study pertains to the instruments used. The BI is an instrument that was designed to measure burden in caregivers of Alzheimer's patients in a developed-world context. Although it has been used previously in South Africa, albeit on a White English-speaking group (Potgieter & Heyns, 2006), and on African populations (Muthoni Kimemia, 2006; The 10/66 Dementia Research Group, 2004), there have not been any large-scale studies that have reported on the reliability and validity of the scale in the African context. Thus, this factor may threaten the internal validity of the study. A possible direction for future research may therefore be to assess the reliability and validity of a translated, adapted version of the BI in the South African context.

A second potential limitation of this study is that it utilised a single standardised scale (BI global score) as an outcome measure. It may have been useful to utilise multiple standardised measures (e.g., activities of daily living, child behaviour, and caregiver coping strategies) as supplementary outcome measures. However, due to difficulties in locating valid, reliable translated versions of standardised tests for use on South African populations (as outlined above), this option was logistically difficult. Nonetheless, future research not operating under the same resource constraints as this study should certainly include, at least, a standardised instrument to assess behavioural difficulties in children under care. This measure could then be utilised to determine if this factor is a significant predictor of caregiver burden in the elderly.

A third possible limitation of the current study, and also one that may have had impact on internal validity, is the quality of the translated instruments. Every effort was made to ensure the high quality of the translation itself and the content validity of the translated instruments (by, for example, utilising techniques such as back-translation and assessing the quality of the translation with the aid of bilingual individuals). However, given logistical constraints it was not possible to utilise more rigorous methods such as using a committee of bilingual individuals, or piloting the questionnaire on a sample of bilingual individuals. Future studies may, however, be able to build on the use of the translated BI and the socio-demographic questionnaire created for this study.

A fourth possible limitation of the current study is that it utilised convenience sampling. Random sampling, while ideal, was attempted but was soon abandoned due to logistical

constraints, primarily relating to time limits within which data could be collected. Future research that does not operate under such constraints will be able to use random sampling.

A fifth potential limitation is that all participants in the current study were members of an organisation that offered formal support. This may have resulted in a lower burden score than would otherwise have been expected. This problem may have been addressed by the use of a matched comparison group. The current research was the first known study that utilised a quantitative approach to data collection on elderly caregivers of OVCs (and was therefore primarily exploratory in nature), and it sampled women from similar socio-economic and geographic backgrounds. However, the use of a comparison group (perhaps comprised of caregivers from the same background who were not receiving any form of social support) may have been useful. However, these approaches were beyond the scope of the current study; they should not be beyond the scope of future studies that operate without the current constraints on time and resources.

A sixth potential limitation of the current study is that it did not elicit specific information on the magnitude of household expenses. Any measure of this variable would have been useful in that one could then have calculated the net income of the household, which may have then been assessed for its ability to predict increased burden. This shortcoming may be addressed by future studies.

A seventh possible limitation is that the questionnaire did not elicit information on the number of ill adults being cared for by the respondent. Although the possible contribution of the presence of ill adults in the household to the BI global score was accounted for, a more precise approach may have been to determine what proportion of those adults were cared for by the respondent.

As is clear from the above discussion, careful consideration of the limitations of the current study suggests fruitful directions for future research. The primary direction for future research, however, should be a longitudinal study that measures the long-term impact of caregiving on the elderly and that includes a demographically matched comparison group of non-caregivers. Such an approach may allow for a more effective assessment of the impact of, for example, particular kinds of social support on caregiver burden. For instance, the current study found an interesting association between whether or not the participant received

assistance in caregiving and the BI global score. Future research might therefore explore the nature of formal and/or informal support systems available to elderly caregivers, factors that determine access to such systems, and the impact of the same on the caregiving experience. A longitudinal design would also allow one to monitor, over time, changes in household composition as a result of the impact of HIV/AIDS, and to measure the effects of those changes on caregiver burden. Within such a design, one might be able to better disentangle exactly which individual and contextual factors serve to decrease or increase the experience of objective and/or subjective burden in elderly caregivers.

In summary, although there are numerous potential limitations to the current study, it has provided a solid base upon which future research might profitably be designed. Additionally, the strengths and innovation of the current study ought not to be neglected: This is the first known study that, in the South African context, utilises a standardised scale and statistical methods to assess the level of burden amongst grandmothers caring for OVCs. The study of elderly caregivers is essential given the evidence in the literature on the risks to OVCs in the absence of proper support and care. Further, and importantly, demographic trends in South Africa (such as population ageing and a high rate of young adult mortality, which have important implications for the number of the elderly in the population as well as the role that they play in society), indicate an urgent need to recognise and respond to the contributions and special needs of this population group.

Practice and Policy Implications

The current study has highlighted that elderly caregivers are a physically, financially, and emotionally vulnerable group. Clinical practitioners and policy decision-makers need to consider ways of addressing these vulnerabilities on micro-, meso-, exo-, and macro levels. The current study focused primarily on micro-level processes by examining the experiences of grandmothers in their homes and with relation to family relationships.

The data presented here suggest that, at the micro-level, elderly caregivers would benefit from direct support and from improved knowledge and skills. A large number of participants in the current study reported that direct input from GAPA-run educational workshops and indabas, as well as financial support derived from skills learned in GAPA-run training courses, helped to alleviate the burden of caregiving. Although the current study did not include a comparison group of individuals who were not affiliated with GAPA (or any similar

programme), it seems clear that direct support in the form of practical input such as home-based respite from care, after-care for school-going children, and assistance with household chores would be of benefit to elderly caregivers.

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APPENDIX A

Burden Interview and Open-ended Questions

The Zarit Burden Interview

Read the following out to the respondent: The questions 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.

Circle the response that best describes the respondent's feelings.

	Never	Rarely	Sometimes	Quite frequently	Nearly always
1. Do you feel that your grandchild asks for more help than he/she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your grandchild that you don't have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your grandchild and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Does your grandchild's behaviour embarrass you?	0	1	2	3	4
5. Do you feel angry when you are around your grandchild?	0	1	2	3	4
6. Do you feel that caring for your grandchild currently affects your relationships with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid what the future holds for your grandchild?	0	1	2	3	4
8. Do you feel your grandchild is dependent on you?	0	1	2	3	4

	Never	Rarely	Sometimes	Quite frequently	Nearly always
9. Do you feel stressed when you are around your grandchild?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your grandchild's care?	0	1	2	3	4
11. Do you feel that you don't have as much privacy as you would like because of your grandchild?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your grandchild?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over because of your grandchild?	0	1	2	3	4
14. Do you feel that your grandchild seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
15. Do you feel that you don't have enough money to take care of your grandchild in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your grandchild much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since caring for your grandchild?	0	1	2	3	4
18. Do you wish you could leave the care of your grandchild to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your grandchild?	0	1	2	3	4

	Never	Rarely	Sometimes	Quite frequently	Nearly always
20. Do you feel you should be doing more for your grandchild than you are currently?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your grandchild than you are currently?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your grandchild?	0	1	2	3	4

Scoring instructions: Add the scores for the 22 questions. The total score ranges from 0 to 88. A high score correlates with higher level of burden.

For all items, the word "relative" (as in the original version of the instrument) has been replaced with "grandchild." For reasons of clarity, the wording of items 4, 6, 9, 10 and 17 have been adjusted. Specific changes include: the use of active language (item 4); employing more specific terms to avoid ambiguity (items 6, 9, 10, and 17); and the substitution of terms with more culturally understandable ones, for example replacing "strained" with "stressed (item 9)."

OPEN-ENDED QUESTIONS: Are there any positive aspects to caring for your grandchild? If yes, please specify. *(If they are unable to respond at all, prompt with suggestions such as "help at home," "companionship," etc.)*

APPENDIX B

Socio-Demographic Questionnaire

1. PERSONAL INFORMATION

First I will start with a few questions about you. Will you please provide me with the following information about yourself:

1.1 Name:				
1.2 Contact Details				
1.2.1 Telephone number:				
1.2.2 Address:				
1.3 Date of joining GAPA				
1.4 Date of joining support group/ Co-op	Support Group Co-op			
1.5 Date of Birth				
1.6 Employment status	Employed		Part-time	Full-time
Specify	Self-Employed		Part-time	Full-time
	Unemployed			
	Pensioner			
1.7 Educational Level	1.9.1 If no schooling:			
	Literate		Illiterate	
	1.9.2 If schooled:			
Specify	< Std. 5	Std. 6-8	Std. 9-10	> Std. 10
	Literate		Illiterate	

2. HOUSEHOLD COMPOSITION

2.1 Please tell me about the people who live in your household: *"Live" means that the person resides in the house for at least 4 months of the year.* ***Include respondent***

Name	**Gender**	**Age**	**Relationship to respondent**	**Health status** *Specify*	**HIV status**
					Test: **Positive:** **Negative:**
					Test: **Positive:** **Negative:**
					Test: **Positive:** **Negative:**
					Test: **Positive:** **Negative:**
					Test: **Positive:** **Negative:**
					Test: **Positive:** **Negative:**
					Test: **Positive:** **Negative:**
					Test: **Positive:** **Negative:**
					Test: **Positive:** **Negative:**
					Test: **Positive:** **Negative:**
					Test: **Positive:** **Negative:**
					Test: **Positive:** **Negative:**
					Test: **Positive:** **Negative:**

2.2 Please tell me about the children under your care: *"Under your care" refers to dependence on the respondent for meeting certain needs, such as being nursed; or that the respondent is guardian of/responsible for X.*

Name	**Does X have any special needs? Specify** **e.g. Bath; dress; feed; medical care**	**No. of years giving care**	**Do you receive assistance in giving care? Yes/No** **If Yes, in what form and for approximately how many hours.**

2.3 Why did you become the primary caregiver of your grandchild/grandchildren?

5.1.1 Death of parent	Mother
(specify if applicable)	Father
	Both
5.1.2 Illness of parent	Mother
(specify if applicable)	Father
	Both
5.1.3 Parent living in another city/province	Mother
(specify if applicable)	Father
	Both
5.1.4 Financial difficulties of parent	Mother
(specify if applicable)	Father
	Both
5.1.5 Other *(please specify)*	

2.3 Please tell me if any of your children/ grandchildren have died of HIV/AIDS?

Yes _____

No _____

Specify (if applicable) which members of the family have died

Name/ Relationship	**Date**	**Was the deceased nursed by the respondent when ill?**	**Did the deceased have any children?**	**Who is caring for the children now?**

2.4 Who is the head of the household? *"Head of the household" refers to the person who makes the final decisions on the general running of the household and on family matters.*

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3. HOUSING CONDITIONS

Please tell me about your living arrangements and about the running of your household:

3.1 What type of dwelling is it?

Formal structure e.g. Brick House	
Informal structure e.g. Shack	
Other *(specify)*	

3.2 Does the household have the following amenities:

Running water	Inside
	On site
	Public Tap
	Other
Electricity	Yes No
Toilet facilities	Flush toilet (inside dwelling)
	Flush toilet (in yard)
	Bucket toilet (in yard)
	Bucket toilet (communal)
	Other *(specify)*

3.3 For approximately how long have you lived in this area? E.g. Khayelitsha; Gugulethu

<1 year	
1-2 years	
3-5 years	
6-10 years	
> 10 years	
All your life	

4. FINANCES

4.1 What are the main sources of income in your household?

Salaries & wages	
Old age pension	
Disability grant	
Child Support grant	
Foster Care grant	
Dependency grant for disabled children	
Loans from family/friends	
Gifts from family/friends	
Money from self-employment	
Other *(please specify)*	

4.2 What is the monthly household income?

< R500	
R500 – R1000	
R1001 – R2000	
R2001 – R3000	
R3001 – R4000	
>R5000	

4.3 What are the three main expenses of the household? Number in order of the greatest expense: 1= greatest expense; then 2; then 3.

Furniture	
Clothing	
Rent	
Food	
Medical	
Loan	
Electricity	
Education	
Other , specify	

5. CAREGIVING

Please tell me more about caring for your grandchild/ grandchildren:

5.1 What are the three greatest problems that you experience in caring for your grandchild/ grandchildren?

_____

_____

_____

_____

_____

5.2 What has been of help to you in caring for your grandchild? *Probe in order to get specific details of how it has been of help.*

5.3 Is there anything else that you would like to say about your experiences of caring for your grandchild/ grandchildren?

6. DAILY ACTIVITIES

Please tell me about your daily activities:

6.1 Name three responsibilities/tasks that are most demanding for you? Please also state how regularly you perform these tasks.

Task	**Demand**		**Frequency**	
	Time		> Once daily	
			Specify	
	Energy		Daily	
			Weekly	
			Monthly	
	Time		> Once daily	
			Specify	
	Energy		Daily	
			Weekly	
			Monthly	
	Time		> Once daily	
			Specify	
	Energy		Daily	
			Weekly	
			Monthly	

7. GAPA

Please tell me about your experiences at GAPA

7.1 Has GAPA equipped you with skills that you now use to earn an income? E.g. sewing

(Please confirm that the respondent learned the skill at GAPA and is currently earning an income from it)

7.2 How else has GAPA helped you to cope better with caring for your grandchild/grandchildren? E.g. Indaba; Education (AIDS; Nutrition; Discipline)

APPENDIX C

Informed Consent Form

University of Cape Town

Department of Psychology

Masters Clinical Psychology Research Study

The experiences of elderly caregivers

CONSENT FORM

All instructions to the interviewer in the questionnaire are in italics. Introduce yourself to the respondent as below:

Good day. My name is _____. I am involved in a research study at the University of Cape Town. We would like to understand your experiences as a caregiver for your grandchild. In order to do this I will ask you a number of questions about yourself and your household. If you agree to take part, everything that you tell me will remain strictly confidential. Your name will not be linked to the information that you provide nor will it appear in any report on the study.

You are not obligated to take part in this study and if you choose not to participate, you will not be disadvantaged in any way. You may at any time during the interview decide that you would like to withdraw from the study. If you decide to do so, there will be no penalties or disadvantage to you.

The aim of this study is to increase awareness of the challenges faced by caregivers and in doing so, to improve state and community support provided to caregivers like you. Therefore it is important that you are open and honest in your responses. The interview will take about 60 – 75 minutes.

Should you require any further information on the study or wish to speak to the researcher about any issues related to the interview or study, please contact Munirah Mangerah on 084 232 2032.Before we start please sign a consent form which I will read to you.

All instructions to the interviewer in the questionnaire are in italics.

Date:	
Venue:	

Thank you for participating in this study. Do you have any questions before we start?

_____

_____

_____

CONSENT

I hereby agree to participate in the research on caregivers conducted by a student from the University of Cape Town. I understand that my participation is voluntary and that I have not been coerced in any way. I also understand that I can choose to stop the interview at any time and that this decision will not negatively affect me in any way.

I understand that this is a research project which may not benefit me personally.

I have the telephone number of the person to contact should I have any questions regarding the interview.

I understand that this consent form will not be linked to any report and that my answers will remain confidential.

I understand that general feedback will be given to members of GAPA on the results of the study in such a way that respondents will not be identifiable.

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Signature of Participant Date

Signature of Interviewer

APPENDIX D

RESULTS OF UNIVARIATE REGRESSION: NON-SIGNIFICANT VALUES

Table D1

Univariate Regression of Continuous Predictor Variables: Excluded Variables

Variable	R^2	Adj. R^2	F	P
Household characteristics				
Adults	0.06	0.04	3.22	0.08
HIV-positive residents	0.05	0.02	1.57	0.22
HIV-positive children	0.04	-0.43	0.47	0.51
HIV-related deaths	0.01	-0.02	0.01	0.94
Chronically sick children	0.04	0.02	2.26	0.14

Table D2

Univariate Regression of Categorical Predictor Variables: Excluded Variables

	R^2	Adj. R^2	F	p
Caregiver characteristics				
Educational level				
Dummy variable 1: <Std. 5	0.05	0.03	2.96	0.09
Dummy variable 2: Std. 6-8	0.04	0.03	2.47	0.12
Dummy variable 3: Std. 9-10	0.00	-0.02	0.02	0.88
Dummy variable 4: >Std. 10	0.05	0.03	2.84	0.10
Chronic illnesses				
Dummy variable 1: one illness	0.03	0.01	1.49	0.23
Dummy variable 2: two illnesses	0.01	-0.01	0.43	0.51
Dummy variable 3: three illnesses	0.00	-0.02	0.06	0.81
Ability to reflect positively on caregiving	0.05	0.03	2.78	0.10
Household characteristics				
Cohabiting spouse	0.01	-0.01	0.48	0.49
Monthly household income				
Dummy variable 1: R500 – R1000	0.01	-0.01	0.33	0.57
Dummy variable 2: R1001 – R2000	0.00	-0.02	0.16	0.70
Dummy variable 3: R2001 – R3000	0.06	0.04	3.26	0.08
Overall housing conditions	0.04	0.02	2.04	0.16

APPENDIX E

Evaluation of Extreme Cases Identified by Residual Statistics Analysis

Table E1

Diagnostic Statistics for Extreme Cases

Case Number	Standardised Residual Value	Cook's Distance	Mahalanobi's Distance	Centered Leverage Value	Covariance Ratio
17	2.32	0.04	0.67	0.01	0.71
19	2.49	0.44	9.46	0.17	0.71