

STRESSORS AND COPING STRATEGIES OF OLDER ADULTS AS  
CAREGIVERS IN THE ERA OF HIV/AIDS: A CASE STUDY OF  
BOTSWANA

A Thesis

Submitted to the Faculty of Graduate Studies and Research

In Partial Fulfillment of the Requirements

For the Degree of

Master of Arts

In

Gerontology

University of Regina

By

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Regina, Saskatchewan

October 10, 2012

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Irene Anabenu Forcheh, candidate for the degree of Master of Arts in Gerontology, has presented a thesis titled, ***Stressors and Coping Strategies of Older Adults as Caregivers in the Era of HIV/AIDS: A Case Study of Botswana***, in an oral examination held on October 5, 2012. The following committee members have found the thesis acceptable in form and content, and that the candidate demonstrated satisfactory knowledge of the subject material.

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## **ABSTRACT**

The HIV and AIDS pandemic in Botswana is having a devastating effect on families and disintegrating traditional family structures. The high HIV infection and AIDS related death rate among youth who are economically and socially the productive sector of the population, has forced older adults into the care of AIDS infected and affected family members. As a result, older adults are becoming the main caregivers instead of care receivers. The purpose of this study was to explore the stressors and coping strategies of these older adult caregivers in Botswana.

The study adopted a case study methodology and used a purposive sampling technique to recruit eight older adult caregivers in Botswana who were age 65 and older and were caring for AIDS orphans. Face-to-face in-depth interviews were conducted with the participants. To bring out the uniqueness of each participant, a detailed description was provided with a focus on the history and sequence of events that led older adults to assume care-giving responsibilities. A within-case analysis was performed to identify themes in each case and a cross-case analysis was also conducted by establishing and comparing cases with common themes.

The findings of this study revealed that older adult caregivers faced four main challenges, which were identified as health issues, financial problems, food insecurity, and stigma and discrimination. According to these findings, participants coped with the challenges of care-giving by depending on social intervention programs such as free healthcare services and monthly food baskets for orphans. The study concludes with recommendations and suggestions for further research.

## **ACKNOWLEDGMENTS**

The completion of this research was made possible by the collaborative effort of all those acknowledge here. First, I would like to thank the eight participants who volunteered their time and information by participating in this research. I also thank the principal of the Kamogelo Daycare Centre and the director of Tirisanyo Catholic Commission in Botswana for giving me the opportunity to conduct this research through their institution.

I extend sincere appreciation to my supervisor Dr. Abu Bockarie for all his encouragement, enthusiasm, and leadership throughout the research process. I would equally like to thank members of my research committee Dr. Mary Hampton and Dr. Twyla Salm for their relentless support and guidance that made the completion of the research possible.

Lastly, I sincerely thank the coordinator of the Gerontology program Dr. Darren Candow for his exceptional leadership and support throughout my studies at the University of Regina.

## DEDICATION

It is with great honour and delight that I dedicate this work to my adorable children; Azoacha, Nkemazem, and Fualefac and my beloved husband and sponsor Prof. Ntonghanwah Forcheh. Guys, it was thanks to your love, encouragement, and understanding that I can now answer Fualefac's famous and heart breaking question at the start of every Skype or phone call "*Hi Mommy, when are you coming home?*" This was the most difficult and painful question I have ever answered. You are guys are my inspiration and mean the world to me. Thanks for giving me the opportunity to realize one of my dreams.

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## LIST OF ABBREVIATIONS

<b>HIV</b>	Human Immunodeficiency Virus
<b>AIDS</b>	Acquired immune deficiency syndrome
<b>NGO</b>	Non-Governmental Organization
<b>UNICEF</b>	United Nations International Children Education Fund
<b>USAID</b>	United States Agency for International Development
<b>WHO</b>	World Health Organization
<b>UNAIDS</b>	United Nations Program on HIV/AIDS
<b>NACA</b>	National Coordinating Agency
<b>OAP</b>	Old Age Pension
<b>BOCP</b>	Botswana Orphan Care Program
<b>RA</b>	Research Assistant
<b>RC</b>	Research Coordinator
<b>GCC</b>	Gaborone City Council

## CHAPTER 1

### INTRODUCTION TO THE STUDY

As the Human Immunodeficiency Virus (HIV) and the Acquired Immune Deficiency Syndrome (AIDS) disease strikes at the heart of the family and community in several African countries, many older adults have been forced to become primary caregivers of their orphaned grandchildren (World Health Organization (WHO), 2002). Botswana is one of the hardest hit countries in Sub Saharan Africa. Because of high HIV/AIDS related death rate in Botswana, the care of orphaned children and the sick has been shifted from youth to older adults. The shift in care responsibilities from youth to older adults has and is expected to have severe health and financial consequences on older adult caregivers because many of the AIDS victims are the youth who in many families are the main income earners. Lindsey, Hirschfield, and Tlou (2003) support this argument by stating that the high incidence of HIV/AIDS among young adults has exposed families to poverty particularly if those infected were breadwinners of the family.

By 2009, an estimated 22.5 million people in Sub Saharan Africa were living with HIV/AIDS (Joint United Nations Program on HIV/AIDS (UNAIDS), 2010), and this number accounted for approximately 64 percent of the global HIV/AIDS cases. The high rate of HIV/AIDS infections in Africa and Botswana in particular, is a major challenge for governments and families especially so because many of these governments and communities are not equipped financially and structurally to adequately deal with the challenges presented by HIV/AIDS. According to May (2003), about 70 percent of those infected with HIV/AIDS live in Sub Saharan Africa and the youth are the most affected.

The impact of AIDS on young people between the ages of 15-49 has significantly reduced the economically active population in Botswana and negatively affected the smooth running of families and communities.

The severe effect of AIDS on youth has also affected children as more and more of children have become and are becoming orphans. According to UNAIDS (2006), the high AIDS related mortality rate among young people has produced about 12 million orphans globally whose care has largely been left to their grandparents, other relatives, and sometimes to orphans themselves. A United Nations Children's Fund (UNICEF) (2003) study supports this view by arguing that in the absence of their parents, a good percentage of these orphans care for themselves, or their frail grandparents care for them. Societal norms and laws the world over, expect adults to care and provide for all children as they are incapable of caring for themselves. However, the impact of HIV/AIDS and other socio-economic factors on many families in Botswana are slowly but steadily eroding these norms laws as more and more children are cared for by their grandparents or relatives.

Across several countries in Africa, the impact of HIV/AIDS on young and active family members has created a support vacuum at household level by contributing to the disintegration of the family support systems. As confirmed by WHO (2002), at least 10 percent of those aged 15 to 49 were estimated to be infected with HIV in twelve Sub Saharan Africa countries. This vacuum forced older adults to step up and become primary caregivers to AIDS orphans. As such, instead of receiving care themselves, older adults have and are taking on the role of caring and providing financial and emotional support to the orphans and infected adult children. These new responsibilities presented older adults

with many challenges, especially so because the responsibilities came at a time in their lives when they are frail and unable to respond to care-giving demands in an adequate manner.

Since the first clinical evidence of HIV/AIDS was reported in Botswana in 1981, the focus of research on HIV/AIDS has been on the impact of the disease on children, youth, men and women, especially pregnant women (UNAIDS, 2002). Although country specific studies are available in Botswana, many of them focussed on the stressors of older adult caregivers and not on their coping strategies. A study by the Ministry of Local Government, Botswana (2006) concluded that food insecurity, the burden of care-giving, health, and financial issues were among the key stressors that older adult caregivers faced. However, the study did not pay much attention to the coping strategies of these caregivers. The findings of a World Health Organization (WHO, 2002) case study on the impact of AIDS on older adults identified older adult caregivers' stressors to include shortage of food and resources, stress, stigma and discrimination, and poverty with little focus on their coping approaches.

A study on elderly caregivers and orphans by Nyambedha, Wandibba, and Aagaard-Hansen (2003) in Western Kenya identified poverty; stress, food shortages, and school dropout among orphans as some of the stressors caregivers faced as they struggled with care-giving responsibilities. However, the study did not focus much on the coping strategies of the participants and so could not paint a complete picture of their situation. The findings of a study by Thupayagale-Tshweneagae (2008) on the psychological effects of care-giving on grandmothers in Botswana, found that grandmothers cared for

about 10 percent of orphans in Botswana, with a majority of them living in the rural areas and poor.

The literature reviewed suggests that although research has focused on the impact of AIDS on older adult caregivers, less attention has been paid to the approaches they adopt to cope with the challenges of caring for AIDS orphans. The limited research on the coping strategies of older adult caregivers in Botswana is a weakness as policy makers and social service workers rely on this information to develop and implement appropriate policies and programs to provide satisfactory services to this population. The focus of this study therefore, was to explore the challenges of older adult caregivers in Botswana with a particular focus on their coping strategies.

### **1.1 Researcher Positionality**

Identifying from the outset the position from which the voice of the researcher emanates is a way of ensuring that those who write, study, and participate in knowledge creation are accountable for their own positionality (Tierney, 2002). I approached this study with previous experience as a Master of Social Work (MSW) graduate from the University of Botswana, a social worker, and a counsellor at the Kagisano Women's Shelter Project Botswana and Lifeline Botswana respectively. As an MSW graduate student, I conducted research on HIV prevention among teenage girls in Botswana, the impact of alcohol consumption on women and their families, and on community empowerment and poverty reduction.

I presented papers in class, at graduate students' conferences, graduate students' seminars, and at an international conference on poverty reduction and adult education in

Botswana in 2004. Further, I have also conducted research projects and presented papers in class on both quantitative and qualitative research methods during the MSW program and the MA program in Gerontology. These experiences have empowered me with hands-on skills and knowledge on how to effectively conduct both qualitative and quantitative research.

As a social worker, I worked with abused women, men, and teenagers by helping them deal with family and marital issues, bereavement, poverty, childcare and rearing, and HIV/AIDS and other terminal diseases. Working with these populations especially with grandparents who were sole carers of orphaned and vulnerable children, got me wondering how these grandparents dealt with the challenges of care-giving without family support. Although these professional experiences improved my interviewing skills and techniques, which are vital in conducting qualitative research, the experiences also increased my curiosity in knowing more about the situation of older adult caregivers. Therefore, my interest in conducting research on HIV/AIDS and older adult caregivers was inspired by both professional and personal experiences as my grandmother cared for me until the age of adolescence when she suddenly passed away.

My grandmother had seven children who provided her with all her needs at old age as the only grandchild living with my grandmother at the time, her love and attention were focused solely on me. But when she died and I went back to my parents, the first few months were the most difficult because my mother's attention and love were not just on me but also on my siblings as well. A lot changed after her death, as I was no longer participating in the decision-making in the household as it was in my grandmother's. With these experiences, I can relate to some of the untold stories of the orphans and the



challenges faced by grandparents in providing care to their grandchildren without the necessary resources and family support.

At old age, many people in Africa depend on their adult children for both financial and emotional support especially so because of the absence of old age pension. Given the AIDS related high death rate among youth who care and provide for their old and frail parents in Botswana and knowing how dependent my grandmother was on her adult children, left me wondering how these older adult caregivers cope with child care, child rearing and above all deal with the responsibilities and challenges of care-giving at old age.

## **1.2 Context of the Study**

Botswana is one of the countries in Sub-Saharan Africa that has been hit hard by HIV/AIDS. In 2000, approximately 36.1 million people worldwide were living with HIV/AIDS, and 70 percent of them were in Sub Saharan Africa, even though only 10 percent of the global population lives in this part of the world (May, 2003). In Botswana, those infected with HIV/AIDS often remain terminally ill in the hospital for months and because of the high number of infected people, health care resources were stretched. According to Lindsey et al. (2003), terminally ill AIDS patients most of whom were youth occupied about 50 to 70 percent of hospital beds in Botswana during the peak of the HIV epidemic. According to Lindsey et al, this high bed occupancy rates was dealt with by creating the home-based care program which was introduced to enable some of the AIDS patients to be discharged from hospitals and sent back to their communities and

families for care. Unfortunately, the main providers of home-based care were frail older adult women and men.

### **1.3 The Study Area**

Botswana is a landlocked country bordered by Zimbabwe, Zambia, Namibia, and South Africa. According to the Government of Botswana census (2001), the country has an area of 582,000 square kilometres. The population of Botswana grew from 1,680,863 in 2001 to 2,038,228 in 2011 as per the Population and Housing Census (Government of Botswana Census, 2011). Thus, the population density is quite low, except in the cities of Gaborone and Francistown, their peri-urban neighbours, and the mining towns. At independence in 1966, Botswana was almost exclusively rural, with an urban population of only 4 percent. Based on the 2011 census however, the urban population grew from 54.5 percent in 2001 to a record 61.1 percent in 2011 (Central Statistics Office Botswana, 2011).

Mogoditshane is one of the largest and fast growing villages in Botswana. It borders the capital city, Gaborone and its population increased from 32,843 in 2001 to 57,637 in 2011, making it the second largest village in the country (Central Statistics Office Botswana, 2011). Mogoditshane is home to both the poor and the rich because of its proximity to Gaborone. The large population and the cosmopolitan nature of Mogoditshane are the main motivating factors for its selection for this study. Figure 1 below provided a better understanding of the location of Botswana on the African map.

Figure 1: The location of Botswana on the African map



Source: [www.google.ca/imgres?imgurl=http://mapmaker.rutgers.edu/355/africa\\_political.gif&imgrefurl](http://www.google.ca/imgres?imgurl=http://mapmaker.rutgers.edu/355/africa_political.gif&imgrefurl)

After independence in 1966, primary and secondary education in Botswana was free, and the adult literacy rate in English was estimated at 70 percent by 2000. In addition, primary health care was predominantly free and universally free for children, pregnant women, older adults, and tuberculosis (TB) patients (Lindsey et al., 2003). However, with so many resources dedicated to the fight against HIV, the government introduced cost-recovery measures that included medical charges and school fees for non-citizens, and nominal medical and school fees for citizens. Most “well to do” citizens and foreigners utilise the rather expensive private schools and medical facilities. Lindsey et al. further suggest that by the start of the new millennium, and at the peak of the HIV/AIDS pandemic, about 47 percent of the population lived in poverty and 45 percent of them were between the ages of 15 and 49 years and accounted for about 89 percent of the reported HIV/AIDS cases in the country.

#### **1.4 Statement of the research problem**

According to UNAIDS (2006), 270,000 people in Botswana live with HIV, and an estimated 120,000 children have lost at least one or both parents to the epidemic. The report also suggests that the HIV/AIDS adult (15-49 years old) prevalence rate in Botswana is about 24.1 percent, which is the second highest in the world after Swaziland. However, the prevalence rate among youth age 15-49 years increased from 24.1 percent in 2006 to 24.6 percent in 2008 (UNAIDS, 2009). Older adults in contemporary Botswana face a range of challenges due to AIDS as most families experience AIDS related diseases, loss of members, diminished family support, and poverty. In the same vein, Clausen, Wilson, Molebatsi, and Holmboe-Ottesen (2007) argue that the current socio-demographic trends and socio-medical pressures such as those caused by HIV/AIDS, urbanization, and labour migration are contributing to the dissolution of the extended family and the isolation and marginalization of older Africans across the continent.

May (2003) argues that poverty reduction measures such as savings and insurance for old age are often not done by those who live a hand-to-mouth lifestyle and that lack of savings exposes those in this category to poverty at old age. According to HelpAge International (2007), about 80 percent of older adults who live in developing countries have neither a regular income nor adequate social support. However, those who can afford to save or invest money often invest in their children who in turn are expected to care for them at old age. Therefore, these adult children become older adults' "saving accounts and old age pensions" and the death of these children is like a loss of life savings and old age pension for some older adult care-givers.

For those older adults who are not only poor but also frail, the death of adult children could mean the loss of financial, physical, and emotional support. Losing such vital support may push poor older adults further into poverty as their sources of income become limited due to retirement, lack of old age pension, and the financial burden of care-giving. Children and older family members in Botswana depend mainly on a strong family support system that is rooted in relentless financial and emotional inputs from young family members. At an advanced stage in their lives, and with impending frailty as well as loss of kin support, many older adults assume the care-giving responsibilities of their sick and dying adult children and later become surrogate parents to orphaned grandchildren (Ferreira, 2004). These new responsibilities pose new challenges to frail older adult caregivers with ill health, especially those with limited sources of resources and support.

In Botswana, care-giving stressors faced by older adults are exacerbated by the HIV/AIDS pandemic and economic poverty (HelpAge International, 2007). According to HelpAge International (2008), about 60 percent of orphaned children live with their grandparents who care for them and their AIDS infected parents. The material and psychological strains of coping with these challenges, especially when the family support system is disintegrating, can be devastating on the health and physical wellbeing of older adult caregivers. Therefore, caregivers are not only burdened by the practical care of orphaned grandchildren and dying kins, they grievously suffer the emotional pain, the trauma of their situation, its demands, and their losses (Ferreira, 2004).

Further, older adult caregivers raised their own children when they were young, had the physical and mental abilities, and the resources. However, instead of enjoying

their retirement many older adults now act as the last line of defence against the destabilization and destruction of their families by the HIV/AIDS epidemic that has robbed many of them of emotional and financial support (Makiwane & Kwizera, 2006). As silent victims of the AIDS epidemic who have lost their main source of economic support, older adult caregivers face increased family responsibilities which expose them to poverty, food insecurity and nutritional problems, poor health, and stigma and discrimination. Although the role of older adults in the fight against HIV/AIDS in Botswana has been significant, research has not adequately focused on exploring their stressors and coping mechanisms. Accordingly, the purpose of this study was to explore the stressors of care-giving with a particular focus on the coping strategies of older adult caregivers of AIDS orphans in Botswana.

### **1.5 Research purpose**

The purpose of this study was to explore the stressors and coping strategies of older adult caregivers of AIDS orphans in Botswana. The study hope to give a voice to older adult caregivers in the process of understanding the challenges they face and how they deal with these challenges, and to use their experiences as the basis for suggesting social intervention programs geared towards ameliorating the situation of caregivers.

### **1.6 Research Questions**

The purpose of this study was achieved by addressing the following research questions.

1. What are caregivers' perspectives of care-giving?

2. What types of challenges do older adult caregivers of AIDS orphans face?
3. What strategies do older adult caregivers adopt to deal with the challenges of care-giving?
4. What suggestions can older adult caregivers offer that may enhance their ability to cope with the stressors of care-giving?

### **1.7 Definitions of key concepts**

Throughout the entire study, words such as “stressors” and “challenges”, “caregivers” and “participants” and “food baskets” and “food rations” are used interchangeably. The following concepts were defined as used in this study.

**Older adults:** According to WHO (2000), older adults in Africa are those in the chronological age of 60 and over. However, for the purpose of this study older adults are those in the chronological age of 65 years and over.

**Orphan:** According to the Ministry of Local Government Botswana (2006), an orphan is a child below 18 years old who has lost one (single parents) or two (married couples) biological or adoptive parents. It is also worth noting that in most or all African countries, a child is anyone under the age 18.

**HIV/AIDS orphan:** HIV/AIDS orphans are children under the age of 18 who have lost one or both parents to the HIV/AIDS scourge (Ministry of Local Government Botswana, 2006).

**Stress:** Lazarus and Folkman (1984) define stress as the relationship between the person and the environment that is appraised by the person as tasking or exceeding their resources and endangering the individual’s wellbeing.

**Stressor:** A stressor is a short or long lasting event that is of an exceptionally threatening or catastrophic nature, which is likely to cause pervasive distress in almost any one (Williams & Kathleen, 1998).

**Caregiver burden:** The subjective experience of problems or strains linked to the caregiver role, which may vary widely depending on the coping nature of the care patient's illness or needs as well as the caregiver's style (Engler, Anderson, Herman, Bishop, Miller, Pirraglia, et al, 2006).

**Care-giving:** refers to the extraordinary care (i.e. usually involving a considerable amount of time and energy) in a home setting and requiring the performance of tasks that may be emotionally, physically, and often times financially straining (Biegel, Sales, & Schulz, 1991 as quoted in Fruhauf, 2003).

**Coping:** is defined as the cognitive and behavioural efforts to manage specific external or internal demands and conflict between them that are appraised as taxing or exceeding the resources of a person (Lazarus, 1991). The coping strategy refers to the specific efforts (both behavioural and psychological) that people employ to master, tolerate, reduce or minimize stressful events (Lazarus & Folkman, 1984).

**Tswana or Batswana:** Tswana or Batswana are the people of Botswana. Tswana or Batswana is an ethnic group in Botswana that migrated from the Eastern part of Africa to the Southern part in the 14<sup>th</sup> century and they are the Bantu speaking people of Botswana and South Africa (Lotha, 2012). The two terms mean the same thing, and so they would be used interchangeably in this study.

**Intergenerational or skipped generation:** HelpAge International (2009) defines skipped generation households as households that occur when an older person, often a



grandparent, becomes the primary caretaker of a child who has lost one or both parents, or whose parents are absent for a prolonged period. HelpAge further explains that this generation is distinct from an older person-headed household where the middle generation may still be present. The generation is also distinct from a child-headed household in which there are usually no older people present, or if they are present, they may be too sick to act as a household head.

**Multi-generational households:** These are households consisting of two or more generations of people, which may include parents and parents-in-laws, siblings and siblings-in-laws, and adult children and grandchildren (Coward & Cutler, 1991).

### **1.8 Significance of the study**

The study was important because of its relevance to policy and practice as well as its contribution to the knowledge base on HIV/AIDS research. It is hoped that the study would stimulate a comprehensive discussion on the challenges of older adult caregivers, and provide a knowledge base on the dynamics of care-giving in contemporary Botswana. The findings of this study may also assist the relevant authorities in formulating and implementing appropriate intervention programs, such as stress management and social welfare programs that would facilitate the work of caregivers. Further, the findings would shed more light on the duties and general situation of older adult caregivers of AIDS orphans. Finally, it is hoped that the study would provoke further research on the coping mechanisms and health implications of care-giving on older adult caregivers in Botswana.

## **1.9 Limitations of the study**

Due to the small sample size, the major limitation of this study was the lack of generalization of the findings to the entire population of older adult caregivers in Botswana. Another limitation of the study was that it did not focus on the stressors and coping strategies of AIDS orphans and the spouses or partners of caregivers who also play a significant role in the care-giving process. Further, the absence of information on the perspectives of significant others in the care of AIDS orphans was a limitation in this study. Although other HIV/AIDS stakeholders such as community organizations, churches, and government agencies played a significant role in the care of AIDS orphans and in supporting older adult caregivers, the study did not focus on them.

## **CHAPTER 2**

### **LITERATURE REVIEW**

This chapter discusses the literature reviewed for the study. It explores the culture of care-giving, HIV/AIDS and older adults in Botswana, stressors of caregivers and coping strategies of older adult caregivers, as well as the theoretical framework of the study.

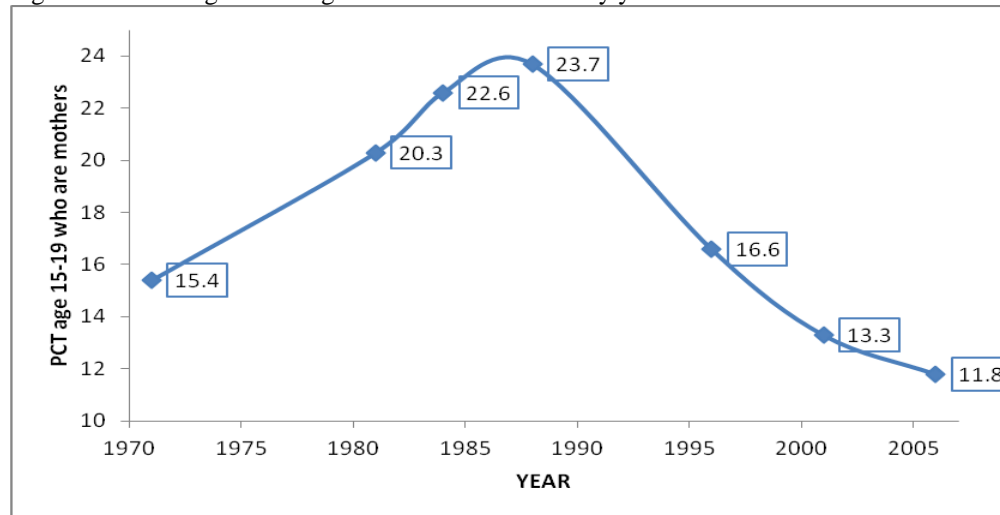
#### **2.1 The culture of care-giving**

Care is regarded in the Tswana culture as a cultural duty and care carries with it some cultural expectations that kins are expected to provide to family members, especially older adults and other members of the community (Leininger & McFarland, 2006). Historically, the extended family in Botswana has been responsible for the care of older adults. However, the HIV/AIDS pandemic, rural to urban and international migration and changing family structures have led to changes in the nature of the support systems (Ice, Zidron, & Juma (2008).

Makiwane and Kwizera, (2006) observed that intergenerational or skip generational households and multi-generational families existed in Botswana and many African countries before the onset of HIV/AIDS. They argue that the vast majority of older adults stay in households with younger relatives and a high proportion of them live in intergenerational households. Ssengonzi (2007) favour that above argument by suggesting that child fosterage is not a new phenomenon in Africa as grandparents and other elderly relatives traditionally have played different roles across the continent in raising children within their extended family system.

In Botswana, like elsewhere in Africa, teenage pregnancy has emerged as a critical issue, particularly in an era of HIV/AIDS. Figure 2 below shows the percentage of teenage mothers in the country from 1970 to 2005, the last year such data was available.

Figure 2: Percentage of teenage mothers in Botswana by year



Source: [http://www.cso.gov.bw/templates/cso/file/File/2006\\_bdsrprt.pdf](http://www.cso.gov.bw/templates/cso/file/File/2006_bdsrprt.pdf)

As shown in Figure 2, the percentage of teenage mothers (15-19 years) reached a peak of 24 percent by 1988. Although the rate of teenage pregnancies had reduced drastically by 2005, over 10 percent of teenage girls in Botswana were mothers by 2006. Most of these young mothers rely on their parents and grandparents for babysitting, including caring for or raising their children. In addition, some grandparents or older adults assume total responsibility by raising grandchildren when their adult children are unavailable due to career demands, schooling, illness, divorce and re-marriage, death, and migration. Many youth also depend on their mothers, as they tend to be unemployed and live with their parents at the time of pregnancy and birth. A study by Hughes, Waite, LaPierre, and Luo (2007) confirms that grandparents participate in the care of their grandchildren in response to the adult child's financial need, divorce, or work commitment. Hughes et al. also state that caring for a grandchild for many grandparents

does not only create a stronger bond between them but brings satisfaction to grandparents, which in some situations may moderate or even outweigh the care-giving stressors they face.

However, some older adult caregivers reluctantly inherit the care-giving responsibility of their orphaned grandchildren. This reluctance is often attributed to the nature of prior relationship between older adults and their adult children. When adult children perform filial responsibilities and other forms of parental care to their elderly parents, the attachment bond between the adult child, parents, and other family members is strengthened (Cheung, Kwan, & Ng, 2006). Silverstein and Bengtson (1997) confirmed this by arguing that both instrumental and affective bonds across generations are necessary to sustain intergenerational solidarity. However, this is not always the case due to socio-economic factors.

Although filial responsibilities are cultural norms and beliefs that Batswana have practised for decades, some adult children still find it difficult to adopt these norms and beliefs probably because of the harsh socio-economic challenges they face. Cheung et al. (2006) argue that the hectic city life and other challenges may drain away the capacity of some adult children to perform filial responsibilities. For instance, the lack of occasional financial and emotional support by an adult child to their parents may sometimes strain the relationship between them and their parents. Further, when adult children who were not supporting their parents come back to them sick and in need of care, some parents may be reluctant to accept such responsibilities. In line with the above assertion, Ice et al. (2008) caution that although the support provided by older adults to their sick children and grandchildren might be morally ideal, more realistically such

support is a flexible cultural norm that operates within a context of individual and group factors. WHO (2002) indicates that the quality of care and the willingness to care sometimes depend on the nature of past relationship between the caregiver and the patient.

Although children play a vital role in maintaining intergenerational households headed by older adults, research has failed to focus on the role of these children in caregiving. In some intergenerational households, children 10 years and older are involved in the care of their siblings as well as frail and ill grandparents who may be unable to perform certain normal daily activities. Some of these care activities performed by children include sweeping the yard, cleaning the house, preparing food, keeping their grandparents company, fetching water, carrying firewood (a major source of fuel in most rural areas in Botswana), as well as doing shopping, and laundry. With the support of adult children, some children live with their grandparent(s) to provide constant support and protection to their grandparents while attending school (Kelley, 2005). The onset of HIV/AIDS has created more intergenerational households in Botswana particularly due to high HIV/AIDS prevalence rates and related deaths among youth.

## **2.2 HIV/AIDS and older adults in Botswana**

Although older adults in Botswana are among the least HIV infected population, they are one of the most affected. Retired and frail older adults are not only taking on the new responsibilities of childcare and rearing but have lost the main source of income and emotional support through the death of their adult children. Caring and supporting children requires financial, physical, and emotional strength and many older adult

caregivers lack these characteristics. In the Tswana culture, young people have always been responsible for the care of older people and children in their families. Adamchak and Adrian (2001) argue that older Africans in particular have historically relied on informal form of support, and they often augment such support with small-scale marketing, gardening, and trading. However, this status-quo is changing as the high HIV/AIDS prevalence rate of 24.6 percent among youth aged 15- 49 years has and continues to destroy the fabric of informal support systems in Botswana and youth family responsibilities are now performed by older adults (National AIDS Coordinating Agency (NACA), 2008b). As the epidemic matures and overwhelms the capacity of the health care system to cope with it, the strains are being borne increasingly by lay caregivers within families (Nesbitt, Ross, Sunderland, & Shelp, 1996).

According to Selwyn and Rivard (2003), for some AIDS infected patients treatment has meant full return to function and health with AIDS experienced as a chronic condition that has little impact on their daily quality of life. They further argue that the treatment has also meant the conversion of death to disability in some cases, with the emergency of the chronic disease phase characterized by exacerbated remission and eventual death from the illness. This also meant prolong care-giving activities and stress for the caregivers as they care for the sick and their children. Caring for healthy children is generally challenging and caring for HIV infected children by older adults can be even more challenging especially because they may not have the knowledge and physical capabilities required to effectively care for these children.

## **2.3 Stressors of older adult caregivers**

In the Tswana culture, as older adults become frail due to aging and reduced physical and psychological abilities, they become the sole responsibility of young family members or adult children. However, rather than receive care as the culture stipulates, many older Batswana have become and are becoming primary caregivers of AIDS orphans and infected relatives. Taking on new roles and responsibilities with impending frailty, may lead to further health and socio-economic stressors for older adults.

According to WHO (2002), these stressors may include though not limited to poor health, financial issues, food insecurity and nutritional problems, and stigma and discrimination.

### **2.3.1 Health issues and access to healthcare services**

For many older adults, old age comes with its own peculiar psychological, physical, and biological challenges. When such challenges are compounded with the grief and trauma of losing an adult child or children to AIDS and then becoming the primary caregiver with limited resources, the effect on the physical and mental health of older adults could be enormous. The distance to the hospital sometimes affects the ability of the caregivers to adequately provide care to their orphaned grandchildren and themselves. Because most of the caregivers struggle financially, they cannot afford transportation to and from the hospitals and do not have the physical ability to walk long distances with children on their backs therefore, tend to traditional doctors and prayers for help. Lindsey et al. (2003) confirm this assertion by suggesting that 74 percent of the caregivers in their study sought treatment from spiritual leaders and traditional doctors instead of the visiting medical clinics. According to HelpAge International (2004), the cost of



transportation from a rural village to the nearest hospital places tremendous strain on the economic resources of the household and on the strength and ability of the older caregiver to plan or save for the future of the orphaned children.

Health care services in many Africa countries are expensive and because most caregivers struggle financially, some of them turn to the less expensive services of traditional doctors located in their communities. In developing countries like Botswana, most hospitals have general practitioners and a few specialists in areas of high demand such as paediatrics. As noted by Clausen et al. (2007) and Ferreira (2004), specialists with geriatric training who understand old age complexities are almost non-existent in healthcare institutions in Africa. This shortage of geriatric professionals contributes to the poor quality of services older adults receive in hospitals and clinics. Discrimination against older adults by some non-specialist health professionals, compounded by the limited access to health services especially in rural areas and low awareness among older adults of their rights and entitlements are some of the health care issues they face (HelpAge International, 2007).

### **2.3.2 Financial challenges and care-giving**

According to Tati (2009), the AIDS epidemic has significantly eroded the principal sources of financial and material support for older adults in several African countries. With limited or no resources, older adults, particularly women, have become the backbone of families and communities in AIDS-ravaged countries (Fernandez-Castilla, 2008). Socio-economic hardship among older adults in Botswana and other African countries is a common phenomenon either because people never earned enough

in their adult life to save for old age or because they invested in their children who do not live long enough to care for them as culture demands.

Lindsey et al. (2003) state that 47 percent of the Botswana population lives in poverty, 45 percent is between the ages of 15 and 49 years, which accounts for about 89 percent of the reported HIV cases. With this background, it is likely that many older adults who care for AIDS orphans may do so with little or no resources. Ferreira (2004) argues that in many African countries, poverty is very common at old age although the exact magnitude and dimension has not been adequately quantified. Ferreira further suggest that one of the causes of old age poverty among this population was due to the fact that many people in their youthful age were either unemployed or employed in the informal sector where wages are low and often not enough for the daily support of their families.

HelpAge International (2004) argues that the high unemployment rate and low numeration packages for the working class hinder people from making financial provisions for old age. Throughout their lifetime, African women especially in the rural areas have poor access to resources with the cumulative effect that in their old age they have insufficient funds for a decent quality of life (Apt, 2007). Previous life of hardship is one of the contributing factors to old age poverty for some older adults. Further, because of limited social assistance programs and services for older adults, poverty experienced in adulthood is likely to deepen with age, which in turn has an intergenerational impact within households (May, 2003). Research has suggested that in South Africa, 85.1 percent of pensioners live in three generational households, suggesting that pensions benefit a far wider segment of the population than the 4.5 percent of the population who

receive it (Ardington & Lund, 1995). They also state that pensioners who are caregivers may spend their pensions on their dependent family members who are either unemployed, infected or affected by AIDS and other terminally ill relatives.

Older adult caregivers may find it difficult to pay for the healthcare cost, school fees, and personal needs of their orphaned grandchildren as the illness or death of an adult child may mean the end of financial support for children and older adults. A 78-year-old adult in a study by WHO (2002) summarised her financial challenges as:

*My sons who were working helped me financially, while my unemployed son worked in the fields. Today no one assists me financially and there is no one to work in the fields. (p. 16)*

Losing an adult child who provides financial support to their children and frail and retired parents may force many older adults into poverty. A study by HelpAge International (2004) argues in support of this by summarising the financial challenges of an older adult caregiver as follows:

*My son was a long distance truck driver plying from Dar es Salam to Mombasa. He was renting a two-roomed house in Muheza town. He was brought home very sick and I had to take him to Muheza hospital where he was hospitalised frequently for about three months. In caring for him, we sold all his property, radio, furniture, cooking utensils, tables, etc in order to raise money for his medical bill and food. He died during the fourth month. Four months later, his wife became very sick and died after two months. This time there was nothing to sell. I really don't know how we managed. They left behind three orphans, one of whom also died shortly after. The two are now aged between 8 and 16 years respectively. The older one was selected to continue with secondary school education but due to poverty, I had to sell some of my land to pay part of her school fees. It is quite tough for me. (p. 12)*

### **2.3.3 Food insecurity and nutrition**

Older adults in contemporary Botswana are becoming heads of families at a time when they have little or no financial resources and physical and emotional abilities

commensurate to the responsibilities that come with this role. The death of adult children may expose their old and frail parents to poverty and food shortages, especially if these children were supporting them financially or on the farm. Many older adult families depend on small-scale farming by the youth for family food production. However, both the employed and the unemployed adult children who help their frail parents by working on the farm or providing financial support to boost food supply in their households are dying from AIDS related diseases. The reduction or termination of the labour force through AIDS related death many lead to a reduction in food production, food security, and nutritional problems for households headed by older adult caregivers.

Lindsey et al. (2003) argue that food shortages in older adult headed households have emerged as an additional source of poor nutrition, poverty, and malnutrition among caregivers, and those affected by the AIDS pandemic in Botswana. According to Kumalo (1990), about 90 percent of older adults lack well balanced diets due to the presence of many dependent relatives in their households, poor budgeting, and financial drawbacks. At old age, nutritional problems can easily be complicated by lack of a balance diet and insufficient food intake, which may lead to malnutrition and osteoporosis in older adults and undernourishment in children. HelpAge International (2004) attributes the progressive decline in immunity associated with ageing partly to nutritional deficiencies in older adults.

However, Topouzis (1999) argues that the effect of AIDS on young adult morbidity and mortality as well as household food security varies depending on the socio-economic status and size of the family, the number and ages of dependent children, and the number and gender of persons suffering from HIV/AIDS. Topouzis also suggests that

households where more women are infected with the virus will have a high level of food insecurity, as women in Botswana are the main family food producers. Further, households with children who are too young to perform house chores and farm activities may be severely affected by food shortages, especially if the household was poor before the death in the family. As heads of the family and surrogate parents to orphans, older adults are responsible for the cost of health care, feeding, pay school fees, clothing, as well as providing the emotional and psychological support that these orphaned children need.

#### **2.3.4 Stigma and discrimination**

Stigma and discrimination is one of the major concerns of older adult caregivers and their AIDS orphaned grandchildren who sometimes are treated by friends and some members of their community with scorn. HelpAge International (2004) posits that stigma and discrimination means prejudice against those affected and infected by AIDS and their caregivers. The stigma is increased by people's general lack of knowledge regarding the causes and the spread of the virus. This ignorance fuels stigma and discrimination against those infected and affected by HIV. The notion that anyone who eats with or touches an AIDS sufferer could contract the virus fuels the stigma and AIDS patients and their caregivers are isolated by friends, relatives, and sometimes healthcare professionals avoid them as well.

Due to stigma and discrimination many HIV infected people and their caregivers are often not willing to disclose their status as they risk losing their jobs, respect, and being isolated by friends and relatives. Stigma and discrimination sometimes forces those

infected to abstain from services (such as free medication from AIDS clinics) and other programs geared towards improving their health. It is against this backdrop that some caregivers may not adopt self-protective approaches such as wearing gloves when cleaning AIDS patients as evidence that their patients are not AIDS victims. According to HelpAge International (2004), the fear of stigma and discrimination reduces caregivers' desire to request professional help, such as home visits by nurses, and prevents them from employing protective measures when attending to AIDS patients under their care.

The Botswana government operates clinics that specifically provide free AIDS drugs such as Anti Retro Viral (ARV) and other services to HIV/AIDS infected persons. Therefore, those who visit these clinics are often presumed by others to be HIV positive. Lindsey et al. (2003) suggest that stigma and discrimination often prevent people living with AIDS and their caregivers from accessing services. Stigma, discrimination, and the fear associated with HIV/AIDS seem to create a barrier that either prevents the caregivers from asking or receiving support (Palattiyil & Chakrabarti, 2008). Therefore, the stigma and discrimination associated with AIDS is among the factors that contribute to the caregivers' risks of contracting tuberculosis, HIV, and other opportunistic diseases during the care-giving process.

#### **2.4 Coping Strategies of older adults as caregivers**

This section reviews literature on the strategies adopted by older adult caregivers to cope with the loss of an adult child to AIDS and the care of orphans. An overview of the various coping strategies caregivers adopted to deal with health issues, financial problems, stigma and discrimination, and the food insecurity and nutritional stressors

they face are discussed in this section of the thesis. The onset of HIV/AIDS has introduced a new trend in many Tswana families where older adults have and are becoming the primary and sole caregivers of AIDS orphans. Although old and frail, older adults have demonstrated tremendous resilience by becoming a powerful force in the fight against HIV/AIDS. Some of the major coping strategies adopted by older caregivers include food rationing, starting small businesses, buying cheap and low quality food items, farming to augment household food supply, and withdrawing children from school.

#### **2.4.1 Coping with health issues**

Although aging may come with health challenges, the stress of losing adult children on whom older adults depend for a livelihood could further compromise their mental and physical health. As if losing a child is not stressful enough, older adults are further challenged by childcare and rearing of their AIDS orphaned grandchildren. In order to cope with these challenges, caregivers may turn to different sources for help. A study by Lindsey et al. (2003) points to the fact that older adults who have financial difficulties accessing the services of clinics tend to go to traditional doctors for treatment. WHO (2002) also found that 24.4 percent of respondents did not seek treatment at all and that about 38.7 percent of those surveyed in the study sought alternative treatment such as praying for health issues rather than use conventional health care services.

#### **2.4.2 Financial coping strategies of caregivers**

The effect of losing an adult child on an older adult goes beyond the emotional and psychological stress and may force them into financial problems. Poverty is one of

the major stressors of care-giving experienced by older adult caregivers. Lack of money because of inability to obtain employment further limits older adults' access to healthcare services, and a vicious circle of illness and poverty develop in which they sell their assets and go further down the hill of poverty (Mohga, 2002).

However, older adult caregivers are determined to provide for their dependents by adopting different approaches. Barnett, Tumushabe, Bantebya, Ssebuliba, Ngasongwa, Kapinga, et al. (1995) suggest that elderly headed-households with financial challenges undertake income-generating activities, such as selling firewood, selling home brewed millet beer, livestock, building fences, handicrafts, and tailoring to supplement their income. UNAIDS (1999) further report that those households that did not have enough income to buy food or pay for healthcare services, funeral expenses, and education costs sold assets to respond to these challenges.

To further cope with the financial burden of care-giving, some older adult caregivers reduce spending by withdrawing children from school so that their school fees could be used in buying medication for sick children and food for the entire household. Sometimes, orphans may drop out of school and obtain employment or work part-time to earn money to support younger siblings and their frail grandparents. According to Naidu and Harris (2006), in cases where the chances of getting paid employment are limited, older adults may encourage AIDS orphans to sell cigarettes and candies, or rent small paid phone booths at shopping malls and on the sides of busy roads where they provide easy access to paid phones as a means of raising money for their families.



### **2.4.3 Coping with food insecurity and nutritional challenges**

The medical expenses that older adults incur during the failed treatment of an AIDS infected adult child or family member and the loss of income (if patients or deceased had a source of income before the illness) due to the subsequent death of an adult child may reduce total household income and expenditure on food. According to Steinberg, Johnson, Schierhout, and Ndegwa (2002), households affected by the AIDS epidemic cope with financial challenges by cutting household spending on food and such cuts often lead to insufficient food in some households. When faced with the prospects of food shortages, households facing financial challenges may fight back by reducing the number of meals per day to meet the consumption needs of their members (Sauerborn, Adams, & Hien, 1996). Further, to improve on family food security when the family breadwinner dies or is terminally ill, family members tend to reduce food consumption and to substitute more expensive food items with cheaper alternatives (UNAIDS, 1999).

As a counsellor at the Kagisano Women's Shelter Project in Botswana, I counselled older adult caregivers, mostly women, who faced food shortages and sometimes had to skip meals to save food for orphaned grandchildren. Food shortages were common among older adult caregivers because many of them did not qualify for destitute food rations distributed monthly by the Botswana Government. Many of the caregivers that were helped at the Women's Shelter were not eligible for the food rations because they had adult children who were expected to support them financially though these children either could not afford or did not care about their parent's well being. Some of these caregivers depended on small vegetable gardens cultivated around their homes and on support from friends and relatives which were unreliable.

The consumption of less and cheap food may result in less intake of nutrients for older adults and children. Poor food intake may have short and long-term negative nutritional implications on the health of older adults and children who at such critical stages in their lives need to consume nutritious food for health reasons. Steinberg et al. (2002) confirm that reduction on food expenditure, consumption, cheap and low quality food, insufficient food, and skipping meals in AIDS affected households have led to increase malnutrition among children and older adults in these households.

#### **2.4.4 Coping with stigma and discrimination**

Many caregivers use denial and withholding information about the HIV/AIDS status of their patients to fight against stigma and discrimination from friends and relatives. For instance, Steinberg et al. (2002) found that most of the participants they surveyed preferred to say the person they cared for or are caring for was suffering from tuberculosis or pneumonia instead of AIDS. Some caregivers deal with stigma and discrimination by lying about their status of those they are caring for and by not using gloves as proof that their patient is not sick of AIDS. According to HelpAge International (2004), an old woman noted that she dealt with stigma by not using gloves when cleaning her AIDS infected sister

*I knew that my sister was HIV positive but I did not want to use the gloves when washing her clothes or bathing her. She brought me some gloves, but I kept them fearing that people might suspect she was HIV positive. (P. 10).*

Due to the belief that church leaders and members do not discriminate against or judge people, many caregivers prefer to solicit the support of church leaders than face the stigma and discrimination from non-church members. Steinberg et al. (2002) suggest that about 30 percent of caregivers they surveyed were coping with stigma and by obtaining

help from religious leaders. Munthali and Ali (2000) argue that during funerals and illness in many Botswana communities, religious groups support members by offering prayers of hope, material assistance, moral, and financial assistance. For instance, some religious groups have set aside specific times to visit and support the sick and/or the bereaved.

## **2.5 Theoretical framework**

This study adopted Lazarus and Folkman (1984) psychological stress, appraisal, and coping theory as an organizing theoretical framework. The two concepts central to the stress, appraisal, and coping theory are appraisal, which is an individual's evaluation of the significance of what is happening to them, and coping, which is an individual's efforts in thought and action to manage specific challenges (Lazarus, 1993). Further, the stress and coping theory provide a framework for evaluating the process of coping with stressful life events (Glanz, Rimer, & Lewis, 2002). The theory posits that when people assess stressful life events, their ability to cope with the stressors depends on their environment and available resources. According to Glanz et al. (2002), a person's assessment of stressful life events depends on what the person perceives to be the impact of the external stressor and how the impact is mediated by the person's appraisal of the stressor and by the socio-cultural resources at the person's disposal.

Rice (1992) argues that according to the stress and coping theory, stress is neither an environmental stimulus, nor a characteristic of the person or a response rather it is a relationship between the demands and the power to deal with them without unreasonable or destructive costs. The basic principle of the stress and coping theory is

cognitive appraisal, which is an individual's assessment of the potential threat of a stressor. The two forms of cognitive appraisals are primary and secondary appraisals. Primary appraisal refers to an individual's judgment of an event as stressful, positive, controllable, challenging or irrelevant (Lazarus & Folkman, 1984). The two basic primary appraisals are perceptions of susceptibility and the severity of the threat. According to the stress and coping theory, appraisals of personal risks, threats, and severity produce efforts to cope with the stressor (Frydenberg, 1997; Rice, 1992). For example, older adults who perceive themselves at risk of starvation may be motivated to obtain employment or sell some of their properties as well as seek social support to cope with the threats (Lazarus & Folkman, 1984). However, heightened perceptions of risk can also generate distress and lack of motivation to take positive steps to deal with the challenges. For example, caregivers who are challenged and frustrated by the stress of care-giving may abuse orphans who depend on them as a coping strategy.

According to Glanz et al. (2002), primary appraisals are mirrored by secondary appraisal and secondary appraisals address one's perceived ability to alter and manage negative reactions to threat and the expectations about the effectiveness of one's coping resources to establish stability between the person and the environment. They also argue that self-efficacy which is the belief about one's ability to perform behaviours necessary to exert control over the situation, may heighten or moderate threatening situations. For instance, when a person appraises a stressor as controllable, he or she will likely adopt coping strategies such as seeking social support and other coping methods. However, if stressors are perceived as highly threatening and uncontrollable, disengaging coping

strategies such as distancing, cognitive avoidance, denial, and drinking alcohol, may be used to shift attention away from the stressor (Frydenberg, 1997).

The stress and coping theory predicts that people search for coping mechanisms if their appraisal of the problem indicate the situation can be changed or dealt with. When the appraisal indicates that the problem or situation cannot be changed the most likely approach to deal with the problem is often denial or ignoring it. Although older adult caregivers may not have the necessary resources to cope with care-giving challenges, their appraisal of the situation is positive as they adopt steps to improve the situation and reduce the stress. Therefore, coping outcomes represent a person's adaptation to a stressor based on their appraisal of the situation. The stress and coping theory is applicable to this study in that it conceptualizes coping as a set of individual cognitive and emotional actions rather than a set of interpersonal traits (Lazarus & Folkman, 1984). They further argue that this perspective implies that the problem does not lead to dysfunction; rather it is the individual's interpretation of the severity of the problem that may lead to the stress experienced and the action taken to deal with the stressor.

Krohne (2002) reviewed the two most popular stress and coping theories, namely Selye's Theory, developed based on experiments on animal subjects, and the psychological stress and coping theory developed by Lazarus and Folkman (1984). Krohne (2002) notes that several limitations of Selye's theory have been identified in the literature, which has led to the adoption of Lazarus' theory as the acceptable standard. Nevertheless, the Lazarus and Folkman (1984) theory has also received some criticisms. In the first publication of the stress and coping theory by Lazarus (1966) it was argued that stress was a specific pattern of psychological, behavioural, or subjective reactions.

For example, Mischel and Shoda (1995) criticized the completely subjective stance on stress conceptualization implied in the stress and coping theory of Lazarus and Folkman. Mischel and Shoda argue further that the fact that most objective features relevant to stress-related outcomes exert their influence via a process of cognitive transformation does not mean that objective features can be neglected. Notably, Krohne recognises that the 1966 Lazarus stress theory has been revised several times (Lazarus, 1991; Lazarus & Folkman, 1984). To acknowledge this weakness, Lazarus (1991) reviewed the concept of stress by suggesting that stress was a relationship (transaction) between individuals and their environment.

## CHAPTER 3

### RESEARCH METHODOLOGY

The focus of this study was to explore and provide an in-depth understanding of the stressors and coping strategies of older adult caregivers of AIDS orphans in Botswana. The method used to explore these stressors and coping strategies involved interviewing the participants. This section therefore, describes the rationale for the research methodology adopted, study population, interview guide, sampling procedure, data collection procedures, and data analysis and interpretation techniques. The chapter also discusses the research ethics process, as well as issues relating to the credibility, trustworthiness and transferability of the findings of the study.

#### **3.1 Rationale for a qualitative research approach**

The philosophical assumption upon which all types of qualitative research are based is the view that reality is constructed by individuals interacting with their social world (Merriam, 1998). Qualitative research is an umbrella term covering an array of interpretive methods such as ethnographic, narrative, grounded theory, case study, phenomenology, and Action research designs. These methods have in common the goal of describing, decoding, translating and understanding the meaning and not the frequency of certain naturally occurring phenomenon in the social world (Merriam, 2009). Therefore, qualitative research is a type of educational research in which the researcher relies on the views of the participants; asks broad and general questions; collects data consisting mainly of words from participants; describes and identify themes; conducts the inquiry in a subjective and unbiased manner (Creswell, 2008). Qualitative research also

implies a direct concern with experiences as lived or felt by people, and has the potential to reveal people's life experiences and the meaning attached to these experiences by them (Merriam, 1998).

Accordingly, a qualitative approach was the most appropriate approach to adequately answer the research questions and address the purpose of this study. A qualitative research design was suitable for this study because it allowed the researcher to personally observe, discuss, and gather first-hand information from the participants. The approach also helps the researcher to create a better understanding and familiarity with the participants which enhanced the researcher's ability to describe, interpret, and portray an accurate picture of the participants and their situation.

### **3.2 Case study methodology**

A qualitative multiple case study design was identified as the most appropriate design to adequately answer the research questions and achieve the purpose of the study. This is because a case study researcher is interested in an in-depth understanding of the holistic nature of a problem by using one or two cases for illustrations (Creswell, 2007). Further, a case study is a qualitative approach in which the investigator explores a bounded system (a case) or multiple bounded systems (cases) over time, through detailed, in-depth data collection involving multiple sources of information including observations, interviews, audiovisual material, and documents and reports, and provide a case description and case-based themes (Creswell, 2007) . Creswell also argues that a case may be an individual, a program, a decision, a group of individuals, an organization,



a neighbourhood, or an event. A case in this study was defined as older adult caregivers 65+ who have cared for or are currently caring for AIDS orphans in Botswana.

Case studies are particularistic, descriptive, and heuristic in nature as they allow the researcher to investigate an identified case or phenomenon (Merriam, 2009). Merriam further argues that particularistic is one of the characteristics of case studies that focus on a specific event or situation where the case is vital for what it reveals about the event or what it might represent. She also notes that the descriptive aspect of case studies denotes the fact that the product is a complete, literal description of the event investigated. For instance, one of the merits of using a case study approach lies in its capacity to focus on several issues concurrently, recognizing and revealing relationships among the cases if any, presenting the findings in prose, and quoting participants verbatim. A case study methodology was adopted for this study with the goal of capturing the individuality of each case, and ensuring that in-depth information on the cases was presented. Gomma, Hammersley, and Foster (2000) argue that case studies capture the uniqueness of cases rather than providing a wider generalization or theoretical inferences of some kind.

### **3.3 Participants and sampling procedure**

Ten potential participants were recruited through a gatekeeper for the study. Those selected were 65+, had cared for or were caring for AIDS orphans, and had been residents of Mogoditshane for at least three months prior to the research. The participants were all Christians, females, and on Old Age Pension (OAP). Eight participants were selected to participate in the study from the ten potential participants that were identified originally. One of them felt uncomfortable with the fact that interviews were going to be audio tape recorded and pulled out and the other did not meet the age requirement and

was not caring for AIDS orphans at the time of the study. Because of the stigma and discrimination attached to HIV/AIDS, the number of participants for this study was originally set at five. However, it turned out that more people wanted to participate in the study, and so the number of participants was increased from five to eight.

A purposive sampling technique was used to identify and select potential participants. This sampling technique gave the researcher the opportunity to select participants who could answer the research questions and help achieve the aim of the study. Based on the researcher's judgement and purpose of the study, this sample was purposively selected in order to collect data that adequately addressed the objectives of the study. According to WHO (2002), the purposive sampling method is based on pre-determined characteristics where the researcher selects the sample subjectively based on these characteristics.

The Roman Catholic Church in Botswana operates socio-economic programs geared towards helping orphans and vulnerable children. With this knowledge, while on a visit in Botswana in January 2011, the researcher identified and approached a church elder in one of the Roman Catholic Churches. The elder was briefed on the purpose of the study, target population, the inclusion criteria, and on the importance of confidentiality. The elder referred the researcher to the Kamogelo Daycare Centre in Mogoditshane. The researcher then contacted the principal of the Daycare Center and explained details of the study to her and the intent to interview grandparents or guardians of some of their students. Further, the method of data collection, and how participants' confidentiality would be maintained were explained to the principal, who then gave the researcher verbal permission to recruit participants through the Daycare. The Kamogelo Daycare Centre is

owned and managed by the Tirisanyo Catholic Commission in Botswana. The general director of the Tirisanyo Catholic Commission in Botswana was contacted by email to obtain permission for participant recruitment through the school and his response was in the affirmative.

The original plan was to recruit participants and conduct face-to-face audio-taped interviews. However, this was not possible as the researcher encountered some challenges and could not travel to Botswana for data collection. Faced with this obstacle, a Research Co-ordinator (RC) who volunteered his services was recruited. He was introduced to the Daycare principal and was responsible for recruiting a Research Assistant (RA) and participants for the study. When it became apparent that the researcher would not travel to Botswana for data collection, telephone and /or Skype interviews were considered as an alternative method for data gathering. The telephone and/or Skype interview method was considered a better alternative for face-to-face interviews because the method would have achieved the goals of face-to face interviews even though it has its own limitations. The Daycare Centre principal and the RC were updated on the new data collection method accordingly and they both supported the idea.

The principal then introduced the RC to the Daycare Centre social worker and suggested that she could help in identifying potential participants as she works with the students and their guardians/grandparents. The RC met with the social worker who agreed to work with the RC and the purpose of the study was explained to the social worker as well as the inclusion criteria, the method of data collection, and the importance of preserving the confidentiality of the participants. A copy of the interview guide was given to the social worker who was now the gatekeeper for the study. The duty of the

gatekeeper was to identify and explain the purpose of the study, data collection method, confidentiality, the inclusion criteria, and interview modalities to potential participants. The gatekeeper also had to take down the details of those interested in participating in the study and arrange for a meeting with the RC and then submit this information to the RC.

After identifying ten potential participants, the gatekeeper met with the RC and gave him a list of the participants who were interested in participating in the study with their contacts and agreed meeting dates and times. The gatekeeper further hinted that those willing to participate were not comfortable doing the interviews in English. Many of the potential participants noted that since they started caring for AIDS infected family members and subsequently the orphans, they have had very few opportunities to tell their story and would like to do so in Setswana (the local language), which they are fluent and comfortable in.

The second problem raised by potential participants was being interviewed via Skype or telephone by the researcher. They indicated that they were not comfortable discussing personal and sensitive issues such as HIV/AIDS on the phone or Skype with someone they did not know and had never met. With these challenges, the University of Botswana student who was initially identified as the research assistant was no longer needed and the Daycare Centre social worker (the gatekeeper) was recruited as the Research Assistant (RA). The language problem was solved by adopting Setswana as the language used throughout the data collection process and the services of a translator was utilized. These changes were made to build trust between the participants and the RC who conducted the interviews. The hope was that the changes would enable the participants to trust the interviewer enough to open up and share details about themselves and their

situation during the interviews without being skeptical. The potential participants were also informed of these changes.

A one-on-one meeting was arranged between the RC, RA, and participants, and it was at the meetings that the RA introduced the RC to the participants. The venue for the first meetings was the participant's home. During the meeting, the RC established participant's eligibility, recruited those who met the inclusion criteria, explained the purpose of the study and the need for consent, as well as the method of data collection to the participants. The changes made regarding the language and data collection method were explained to the participants again. The ages of the participants were determined using their Omang (National ID card).

The importance and meaning of the participants' consent was explained to each of the participants, and those who met the inclusion criteria and were interested in the study were recruited as participants. The participants were required to sign the consent form or give verbal consent for their participation in the study after the contents of the consent form were explained to them. All the participants provided verbal consent, which was indicated on their consent form. Of the ten potential participants identified, eight of them agreed to participate in the study.

### **3.4 Interview guide**

Interviews are the most preferred and appropriate method of collecting personal and detailed data from participants in a qualitative research study like this one; therefore, an interview guide was developed. The literature review, purpose of the study, the research questions, and my personal experience growing up with my grandmother until

the age of adolescence guided the development of the interview guide. Further, my professional experience in conducting research at graduate level and working with both young and older women caregivers also guided the development of the interview questions. The interview guide was made of two main parts. The first part of the guide collected participants' socio-demographic data to facilitate a better understanding of participants' situations and the taped recorded interviews. Part two of the interview guide comprised of open-ended questions that collected data on the stressors, coping strategies, and participants' suggestions on different approaches that could be used to assist them with care-giving responsibilities.

### **3.5 Data collection**

The primary data collection method for this study was face-to-face interviews with the participants. Two interviews were conducted at the participants' homes. The first interviews were conducted within one week. The socio-demographic data of participants were collected during the first interview. At the end of the first interview, the RC, RA, and the participants agreed on the date and time of the second and last interview. The second interviews started a few days after the first interviews ended. The second interviews were lasted between 40 and 60 minutes as some participants were slow in responding to questions. At the end of each interview, the RC and RA noted their observations as well and the data were collected over a period of three weeks.

With each participant's permission, the second interviews were audio tape-recorded. The interviews collected data on the stressors, coping strategies, and suggestions for best practices from the participants. To protect the identities of the

participants, the information they provided was assigned a unique number or pseudonym in order to protect and guarantee their confidentiality. Finally, to facilitate a holistic understanding of each case, both verbal and non-verbal communication cues expressed by the participants during the interviews were also documented.

Observation of the participants' homes was done during the interviews. For instance, such information as the type of house (s) and the living conditions of the participants was gathered. The activities of the participants and members of their households were also observed. The focus on participants' activities and their homes was to help paint a clearer picture of their situation. However, it is worth noting that observation of the participants was limited due to time constraint. In some cases, field notes taken during the interviews and data collected from the first interview were used to clarify a few doubts in the taped-recorded data. Immediately after each interview, the interviewers' thoughts and impressions were recorded in a journal to preserve the initial impressions of the interaction. The data were collected with permission from the participants and in full compliance with the University of Regina Research Ethics Board and the Botswana Research and Development Ethics Committee (See appendix D).

### **3.6 Data analysis and interpretation**

Data analysis is a process of making sense out of the information collected by consolidating, reducing, and interpreting all the information gathered from participants' interviews and the researcher's observations (Merriam, 2009). In addition, Yin (1994) suggests that data analysis in a case study consist of examining, categorizing, tabulating, or recombining the evidence to address the initial proposition of a study. For this study,

simultaneous data collection and analysis were done by reviewing field notes and analyzing the data collected during the first interviews as data collection progressed. The participants' responses from the first interview were translated into English, and the papers were scanned, encrypted, and sent to the researcher by email. After collecting socio demographic data from the first few participants, the data were entered into Microsoft Word and a folder was created for each participant where their information was stored. Where necessary the transcribed data were related to field notes to ensure accuracy and to deal with any discrepancies. Where the information provided was not clear, the RC was notified and the participant in question was contacted for clarification.

The audio taped-recorded data from the second interviews were transcribed into Microsoft Word and added to the participants' folders, which were created after analysing data from the first interviews. The transcription process started with a verbatim transcription of the recorded interviews and only one interview was transcribed at a time. A downward line numbering was added on the left hand side of the page and space was created on the right margin to facilitate data coding and analysis. The numbering was done in sequence until the end of each interview. The transcription of each interview started on a new page and the numbering started from one and continued until the end of the interview with interview questions in bold.

Data coding was used to trim down the large amount of recorded data to themes and categories. Coding is the processing of interviewee's responses into categories that bring together similar ideas, concepts or themes in the data (Rubin & Rubin, 1995). The transcribed data were read and identified themes were coded with abbreviations that identified the themes. For instance, stressors were coded as "SS", coping strategies as



“CS”, and suggestions as “ST”. This method of coding was very helpful going forward as it was easier to locate vital information. Mayring (2000) refers to this coding process as inductive content analysis with open coding whereby each section of the interview transcript is coded using words to denote the different themes focused on in the study.

A holistic data analysis was conducted where a step-by-step description of each participant, including the researchers’ observations was provided to paint a clearer picture of each participant and their situation. A within-case analysis was also performed where themes from each case were identified and used in analyzing and understanding the case. A cross-case analysis, which involves comparing and contrasting identified themes, was also performed by analyzing and establishing the relationship between and among cases.

The analytic data analysis strategy was used to facilitate clarity and a better understanding of the issues under investigation by analyzing the key themes in the data to bring out the uniqueness of each case before comparing the cases. Hancock and Algozzine (2006) state that each new piece of information should be examined in the light of the fundamental research questions to maintain the focus of the researcher. Therefore, data that addressed the issues under investigation and emerging themes were identified, grouped into meaningful categories, and interpreted to answer the research questions. These categories consisted of emerging themes related to the stressors and coping strategies of participants and their suggestions. Other themes that emerged from the data were placed in the emerging themes category for analysis and interpretation.

### **3.7 Credibility and reliability**

Lincoln and Guba (1985) relate that credibility, transferability, dependability, and confirmability are some of the key criteria used in evaluating qualitative research.

According to Lincoln and Guba, credibility focuses on the degree to which the findings make sense given the data presented. The credibility of the findings of this study was supported by the holistic presentation of the data and by using verbatim quotations from the participants to re-enforce arguments presented. Further, to guarantee the credibility of the findings participants were contacted to clarify inconsistencies identified during data analysis especially with the first interviews.

According to Merriam (2009), triangulation of data through the use of multiple sources of data involves comparing and cross-checking data collected through observations and interviews from people with different or the same perspectives. The findings of this study were the product of data collected from multiple sources, a process known as triangulation. These sources included documents (National ID card), observations, and face-to-face interviews with participants, and data were interpreted and presented holistically to portray an accurate picture of the participants' situation.

Merriam (2009) defines reliability as the extent to which research findings can be replicated. That is if the same study were repeated, would the same or similar results be obtained? The findings of this study can be replicated given that the interview guide was carefully designed with a focus on the themes being investigated and well implemented. However, considering that human behaviour changes constantly as dictated by their environment and life experiences, their worldview may change accordingly. Therefore, replication of this study may not produce the same results.

Lincoln and Guba (1985) argue that transferability in qualitative research involves providing a detailed portrait of the research setting and participants' experiences. Transferability was achieved in this study by providing a detailed description of the research settings based on observations and interviews. For instance, description of the study setting and individual circumstances of the participants was provided.

### **3.8 Research assistant**

A research assistant with a Social Work academic background and extensive work experience was recruited to assist with data collection. She assisted in the identification and recruitment of participants, translation of the interview questions from English to Setswana and the participants' responses from Setswana to English. The research assistant was paid P1000.00 (\$173 at exchange rate of US\$1.00 = P5.8) for her contribution in the study. She was paid at the end of the data collection process as per the contract.

### **3.9 Research co-ordinator**

The Research co-ordinator was a Professor from the Department of Statistics at the University of Botswana with 20 years of experience in teaching, supervising thesis and dissertations of graduate students, and conducting research. He volunteered his services by co-ordinating the entire data collection process. He understands Setswana (the local language used in the interviews) though his speaking ability was basic. His responsibilities included recruiting the research assistant, the participants, and keeping the researcher updated on those days that interviews were conducted. He taped-recorded all the interviews and wrote down participants' responses during the socio-demographic data

collection process. The research co-ordinator transferred the audio-taped interviews into two CDs, encrypted them, and sent them to me in Canada via Courier. The interviews were then transcribed and analyzed by me.

### **3.10 Ethical considerations**

An ethics approval was obtained from the University of Regina Ethics Board and the Research and Development Ethics Committee at the Ministry of Local Government in Botswana for data collection. In order to recruit participants through the Kamogelo Daycare Centre, permission was obtained from the managing authority of the Kamogelo Daycare Centre.

All the participants confirmed their participation in the study by giving verbal consent at the beginning of the data collection process. The participants were assured that protecting their data in order to preserve their confidentiality was the researcher's priority. The participants were also advised that their participation in the study was optional and that they had the right to withdraw from the study at any time without consequences. However, they were also informed that if they withdrew from the study when the data analysis process had begun they might terminate their participation but may not be able to withdraw their data at that stage of the research. Preserving the privacy or confidentiality of participants was of utmost importance, and was guaranteed by using pseudonyms in place of participants' names.

Further, it was anticipated that the interviews could bring back memories of previous stressful events and the participants may need the services of a counsellor. With permission from Lifeline Botswana, their toll free counselling phone number (0800 600

895) was given to participants in case they needed some counselling after the interviews. All the participants were given P50.00 each for their tea. This tea was a gift to the participants and not a reward for participating in this study, as their participation was voluntary. Considering that the Daycare Centre was an NGO that depends on donations for survival, a P500.00 donation was given to the Daycare as support. For the confidentiality of participants to be further preserved, access to the data was limited to the researcher, the research co-ordinator, and the research supervisor. The data will be protected by preserving the audio tapes in a locked cupboard and computer files and access would require the use of a password. The data would be stored for three years after which the electronic file would be deleted and the audiotapes destroyed.

## **CHAPTER 4**

### **RESEARCH FINDINGS**

This chapter presents the findings of the study. The focus of this chapter was on using the findings to answer the research questions that provoked this study. The research findings presented in this chapter focused on case summaries, participants' perspectives on care-giving, the stressors experienced by caregivers, and the strategies they adopted to cope with the stressors. Suggestions from the caregivers regarding what could be done to improve their situation and to enable them better provide care to the orphans were also focused on. The chapter concluded by discussing the new themes identified from the data.

#### **4.1 Case summaries**

With randomly chosen pseudonyms assigned to the participants to protect their identities, a brief summary of each participant was presented. The summaries provided information on the socio-demographic and economic conditions of eight caregivers who participated in the study. The eight participants were: Rose, Monica, Neo, Mpho, Lesego, Refilwe, Banyana, and Mary.

##### **Rose**

Rose was a 65-year old single mother of three daughters. She started primary school but dropped out to take care of her parents' livestock. Rose had a compound that comprised of two houses and each of the houses had two bedrooms and a living room. She rented out one of the houses and occupied one with her two adult children and three orphaned grandchildren. The houses did not have running water and electricity and the

family used firewood for cooking and paraffin for lighting. The family collected drinking water from a neighbour's compound free of charge.

Rose was employed as a restaurant attendant until 1999 when she quit her job to take care of her AIDS infected sick daughter. Before her daughter's illness, Rose and her daughter worked to support the family as two of her younger daughters were unemployed. In late 1999, Rose's older daughter, who was a single mother of two children age eight and nine years, became pregnant. She became ill as the pregnancy progressed and was later diagnosed with AIDS. Although she was placed on medication, her condition continued to deteriorate so she quit her job, as she was too weak to go to work and to take care of herself. As noted earlier, Rose also quit her job to care for her sick and pregnant daughter, and her two grandchildren.

When Rose's daughter became very sick, Rose took her to her parent's house where her siblings also lived because she ran out of money. However, she soon realized that her family was very unwelcoming and treated her and her sick daughter with scorn. For example, since her daughter was too weak and unable to take a bath by herself, Rose had to bathe her. Because of this, whatever Rose touched or used in the house was avoided by her parents and siblings and they refused to eat food prepared by Rose. Rose was very emotional as she described the negative attitude of her family towards her and her sick daughter during the interview.

In 2000, Rose's sick daughter passed away two days after giving birth to a baby boy, leaving behind three children. The responsibility to care for these children fell on Rose even though she was not financially ready. Rose was stressed by the fact that she had three orphaned children to care for with the new born HIV positive and did not have

a source of income. She was deeply worried and frustrated, cried, and prayed to God for help as she had no body to turn to for support. Caring for the new born HIV positive grandchild who was often sick, meant Rose could not work to support the her family.

After the death of her daughter, Rose moved back to her house with the orphans and applied for assistance at the Botswana Orphan Care Program (BOCP). While waiting for assistance from BOCP, Rose decided to look for menial jobs in her neighborhood with the baby on her back as she had to feed her family. After a few months, the orphans started receiving three food baskets every month as well as P800.00 from BOCP. In 2008, the quantity of the food basket was reduced and the money also reduced from P800 to P500. The orphans received food baskets from BOCP until when two of them turned eighteen and were no longer eligible for BOCP. At the time of the interview, only the youngest orphan was receiving assistance from BOCP. However, Rose's two daughters had also picked up employment at the Ipelegeng program, which was established by the government of Botswana to reduce unemployment and poverty among those without skills and older people who are capable and willing to work.

Rose's entire family, that is, two daughters, three orphans and Rose herself, depended on the monthly food baskets from BOCP, the monthly food ration the youngest orphan was receiving from the clinic, and the pay cheques of her two daughters. In Botswana, all children aged 0-5 years old receive monthly food rations from the clinics. The food basket from BOCP and the clinic contained food items such as beans, milk, maize meal, cooking oil, sugar, Tsabana (sorghum and soy vitamin fortified porridge for children), infant formula where necessary. All the children on BOCP, who were in school also received free school supplies such as school uniforms, books, pencils, pens, etc.



Rose was happy that her grandchildren were not picky when it came to food as they ate whatever was available. Occasionally however, Rose would buy chicken and rice for the children as these items were not included in the BOCP food basket. During these challenging times when Rose's only source of food and income was BOCP as she was not old enough to qualify for Old Age Pension (OAP), she started a small business by selling cigarettes, matches/lighters, candies, and chibuku (local beer made from sorghum) in front of her house to raise money for her family.

Although the food basket from BOCP was accompanied by P500, most of the money was spent mainly on the youngest orphan who was born HIV positive and was frequently sick. When Rose took him to the hospital one day the doctor said the child was not eating enough fruits and vegetables to improve his immune system and general health. Rose told the doctor that she could not afford the food items because she was unemployed, and her grandchildren depended on BOCP for food and that the program does not provide vegetables and fruits. The doctor gave her a list of fruits and vegetables that the child needed and she took it to the social worker who then included these items in the child's food basket.

Thanks to the ARV that Rose's HIV positive orphaned grandson was taking; all the frequent illnesses disappeared and at the time of the interview the child was doing well both in health and school. When Rose's grandson turned three, she registered him at the Kamogelo Daycare Centre so that she could take break from childcare and complete the household chores before the children returned from school. When Rose's youngest orphan was old enough to enter primary school, she visited public primary schools close to her house to obtain admission for him. The first school rejected the child and Rose

thought the rejection was because the child was HIV positive. Rose was upset but did not want to blame anyone for discriminating against her because her own family did same when her daughter was sick. Eventually, Rose got the child admitted into a different school.

Rose found some financial and food security relief when all her grandchildren were in school. In Botswana, primary and secondary education is free, and children in both primary and secondary public schools are provided two meals a day at school. Thus, Rose's worried was providing the orphans with dinner on weekdays, and breakfast, lunch, and dinner on weekends.

Rose complained that since 2008, the quantity of the food basket has reduced and the money also reduced. Rose believed the reductions contributed to the food insecurity in her household, and suggested that the government should increase the quantity of the food basket. Although Rose's situation did not look very good as two of the orphaned grandchildren turned 18 and were no longer receiving food baskets, were unemployed, and depended on her, she appeared very positive, hopeful, and grateful. However, Rose was still grieving the death of her daughter although she believed that talking about her problems with others have helped her in dealing with the trauma of losing adult child and a bread winner and the challenges of care-giving. Rose indicated that she suffered from stress, hypertension, and was on prescribed medication for hypertension. Rose was also taking Maringa tea that supposedly helped in reducing stress and she was referred to this tea by a friend. She also dealt with stress by keeping herself busy most of the time so that her mind was not pre-occupied with the life challenges she had experienced.

## **Monica**

Monica was a 72 year old widow whose husband died many years ago and she became the head of her household. Monica had some primary education but did not complete primary school. She was on high blood pressure treatment and Maringa tea that kept her stress levels and blood pressure in check. Monica had two houses in her compound and the houses did not have running water or electricity. The family used firewood and paraffin in cooking and lighting respectively. Nine family members lived in Monica's household at the time of interview. This included her 33 year old son, a granddaughter and her two children (Monica's great grandchildren), two orphans (ages three and thirteen) and a 22 year old grandchild who was an orphan before turning 18, an eight year old foster child, and Monica herself.

As a mother of two children, Monica was a stay home mother and when her children grew up, she became a subsistence farmer. She cultivated maize and other vegetables to feed her family and sold some of her produce to raise money. It was difficult for subsistence farmers, like Monica, to make a living from farming because of scarce or limited rainfall in Botswana. This factor forced many farmers to live a hand-to-mouth life style, as their harvests were sometimes not enough to feed their families, let alone saving for future use. Thanks to the Botswana non contributory OAP Program which helps seniors 65+ to meet basic personal needs, Monica had a steady source of income.

When Monica's daughter got married and moved out of the house; her brother, who was employed and unmarried, continued to live with Monica. Being the only son in the family, the Tswana culture expects him to reside with, or close to his parents, in this

case his mother, to take care of them. In Botswana, children build their houses on the family land where their parents live, to ensure that they are better able to support and care for each other when the need arises. The Tswana culture requires adult children to take care of their old and frail parents so children are encouraged to live close to their parents and to care for them until they die.

As mentioned earlier, Monica's daughter moved to her husband's house when she got married, and the couple was blessed with three beautiful daughters. Unfortunately, the marriage failed and Monica's daughter was given custody of the children and the house she owned with her husband. Two years later, her ex-husband went back to court, which awarded him the house. Monica's daughter and her three children were kicked out of the house, and they moved back to stay with her since her daughter was unemployed and could not afford to rent a place to stay. Monica's daughter later relocated in South Africa leaving the children with Monica.

Monica became the primary caregiver for her grandchildren even though she had limited resources and physical abilities. Two of the three granddaughters completed secondary school, obtained employment and were supporting Monica and their own children financially. Monica's granddaughters were single parents and Monica cared for their children as they were employed. Unfortunately, one of the granddaughters died of AIDS related causes in 2000, leaving behind two children age one and ten years old. Monica was sixty years when her granddaughter died in 2000, and since the qualifying age for the non-contributory OAP in Botswana starts from sixty five years, she was not eligible for the benefit at that time. Because one of the granddaughters had no job, and

depended on her two siblings who were employed for support, losing a source of income was financially challenging for the entire family.

The situation was compounded by the fact that Monica could no longer do farm work since she had to provide childcare for her grandchildren. To complicate matters, the youngest of the three granddaughters completed junior secondary school, was unemployed, and a single mother of one. The monthly food ration from the clinic for children 0-5 years helped to boost the food supply in the household as one of the granddaughters was still working and supporting family. Monica also registered the two orphans with BOCP and started receiving the monthly food baskets. These two food sources helped a great deal to ameliorate the food supply in Monica's household.

In 2009, the only granddaughter who was working and supporting her late sister's kids, grandmother (Monica) and the rest of the family died two weeks after giving birth. Just when Monica thought the worst was over, she had to start caring for two weeks old baby. Monica was devastated by the loss of her granddaughter and the challenge of caring for a two-week old baby. Monica was on OAP by 2009 and her son was also supporting the family financially; however, the support was not enough to care for the entire family, especially with the loss of two sources of income. However, Monica had a vegetable garden in her backyard that sometimes helped to augment the food supply in her household. Monica's granddaughter also died in 2011 from AIDS related causes and was survived by two children age 12 and 21 years.

Monica developed high blood pressure from the stress of losing two granddaughters and becoming the primary caregiver though frail. The stress was evident when the interviewer asked Monica how the death of her granddaughters and care-giving

has affected her health, as she became emotional and tearful. At the time of the interview, Monica's only surviving granddaughter had a child, was unemployed, and therefore, unable to provide any financial help to the family. Monica indicated that her oldest great grandchild was also very helpful with childcare and house chores. However, her daughter who lives in South Africa was very unhelpful, even when she paid the family occasional visits. The two-week old great grandchild was three years old at the time of the interview, and attending Kamogelo Daycare Centre. When the child started school, Monica got a job at the Kamogelo Daycare Centre to raise money for her family.

Monica also cared for a foster child who she adopted in 2006. The foster child was born in 2004 to a woman who was her mother's neighbour. The woman abandoned the child with Monica's frail mother. When Monica visited her mother and found the child, she reported the case to the police who asked her to take care of the child until further notice. The foster child was eight years old at the time of the interview and attending primary school.

Monica received three food baskets from BOCP and P500 for each food basket. She takes home a total P1500 every month. She joined a group of four caregivers who were make a monthly contribution of P100 ( $100 \times 4 = 400$ ) which was given to a member until they all received it. Monica used this money and the P1500 from BOCP to build a small house in her compound which was put on rent. Monica had plans to build another small rental unit so that the orphans would depend on the houses for support when she dies. As stressful as Monica's situation was, she was grateful and motivated by the support from the Government and the strength from God that kept her going.

## Neo

Neo was a 73 year old widow who lived with ten family members in a large compound of five housing units and the main house. The compound comprised of four two bedroom houses and a one room house as well as the three bedroom main house which at the time of data collection was being extended. All the houses had running water and electricity. Neo had seven children, suffered from high blood pressure, and was a livestock farmer (cattle and goats).

When Neo's husband passed away, her oldest son took control of the farm. The family also had a large amount of undeveloped land and some of the land was taken by the government of Botswana for development purposes. Neo was then compensated financially for land. At the time of data collection, Neo was caring for five orphans (three of whom were eighteen years and older and unemployed), four adult children, one great grandchild, and Neo herself. Three of Neo's seven children had passed away. One died in a car accident in 1995, two died from AIDS related causes, and all three deceased were survived by children. Two of Neo's deceased daughters were employed single mothers and lived with her before their death. At the time of data collection, Neo had four unmarried adult children living with her. One of them was a driver; the eldest son worked on the family farm and the other two are unemployed and depend on Neo for food and other basic needs. With seven children, Neo spent much of her early adult years on childcare and rearing and just when she thought it was time to relax and let her children take care of her but AIDS forced her back into childcare and rearing again.

Neo's daughter who died in a car accident in 1995 left behind two children age three and seven years old. At the time of data collection the children were nineteen and

twenty four years old. One of the orphans had tuberculosis (TB) but was treated and was doing well health wise at the time of data collection. Before her sudden death, Neo's daughter worked to support her children and the family. Neo's nineteen-year old grandchild was still in school; however, the twenty-two year old had completed junior secondary school but was unemployed and depended on Neo for his daily needs. As Neo was trying to accept the death of her daughter and move on, AIDS struck her family.

In 2000, Neo lost a daughter to AIDS who was an unemployed single mother with a sixteen-year year old child. Neo was emotional when discussing the death of her daughters, and although the interviewer was willing to suspend the interview, she insisted on continuing with it. She apologized for the incident, and noted she thought she had dealt with these emotions. The incident was probably an indication that Neo was still grieving the loss of her daughters. As if losing two children was not enough, another daughter died of AIDS related causes in 2004. She also left behind two children who were two and seventeen years old and ten and twenty five years old at the time of data collection. The ten year old was still in school and the twenty five year old had completed secondary school but was unemployed and still living with his grandmother (Neo).

Neo's sources of income were decreasing as the number of dependents was increasing. However, as a livestock farmer and with the land compensation from the government she could afford to provide for her family even without government support. Although five unemployed adults and four children lived in Neo's household and depended on her for their daily needs, she was able to provide for them by utilizing BOCP, OAP, food rations from clinics, school feeding, her farm, and the compensation from the Botswana Government. At the time of the interview, Neo's main activities were



attending Kgotla (village) meetings, weddings, church services, and funerals. She no longer performed household chores as her adult children and grandchildren took care of household and farming activities.

### **Mpho**

Mpho was a 68 year old woman who never went to school and was never married. However, she lived with three orphaned grandchildren at the time of the interview. She had one daughter who was a single mother of three young children. Mpho had a house that was demolished some years back by the Gaborone City Council (GCC) for illegal settlement but she was never compensated for her house. After the council demolished her house, Mpho and her daughter started life from scratch with little or no money. Without a job or money, Mpho could not build a house for her family. Her daughter was employed, but her monthly pay cheque was not enough to adequately feed the family and Mpho and her daughter could not afford to rent a place for their family. In order to get off the street, Mpho decided to rent a piece of land in someone's yard for P90 per month to build a small shack with corrugated iron sheets. She moved into the shack with her family, as her daughter had only one child at the time. However, her daughter gave birth to two more children while living in the shack. The house or shack had no electricity, no running water, and firewood was used for cooking and paraffin for lighting. Mpho's daughter worked and paid the P90 monthly rental and supported the family financially while Mpho babysit her grandchildren and took care of household chores.

In August 2011, Mpho lost her only daughter to AIDS after a protracted illness. She left behind three children who were six, ten, and fourteen years old. She was the

breadwinner of the family and Mpho and the children depended on her for financial and moral support. After her daughter's death, Mpho and the orphans depended on the monthly non-contributory OAP that she was receiving from the Botswana government. She also applied for assistance from BOCP as well as a low-income house from the GCC and at the time of the interview, she was anxiously waiting and praying for a positive response for the GCC and BOCP applications.

Mpho could apply for a job at the Ipelegeng Program at the Ministry of Local Government that employs older adults and low skilled individuals but she did not have childcare especially when the children returned home from school. The six year old orphan attended the Kamogelo Daycare Centre, the ten years old attended a public primary school, and the fourteen years old attended secondary school. Since public primary and secondary education in Botswana are free, Mpho's orphaned grandchildren received free education and meals at schools. However, she had to buy school supplies for the children as their admission into the BOCP program was still pending. Mpho would have loved to have a small vegetable garden to augment food supply in her household but lacked access to land. Mpho kept her house very clean although her living conditions were very challenging and troubling, especially given that children were living in such conditions. Fortunately, Mpho and her three grandchildren had no health issues, but she was not happy that BOCP was taking so long to register her grandchildren for assistance.

## **Lesego**

Lesego was an 82 year old widow whose husband passed away about 15 years ago leaving her with three children to care for. She suffered from hypertension and was on hypertension medication at the time of data collection. Lesego and her husband were livestock farmers. Lesego was caring for nine people in her household and this included four orphaned grand and great grandchildren, two adult children (a daughter aged 55 and a 49 year-old son), and 2 adult grandchildren who were 20 and 24 years old (children of the 55 year -old daughter). Lesego lived in a compound of two houses and each of the houses had two bedrooms and a living room. The houses had running water and electricity and the family used gas for cooking. Lesego had three adult children who were all living with her before the untimely death of one of them.

Between 2001 and 2005, Lesego lost a daughter and a granddaughter to AIDS. She started caring for orphans in 2001 when her daughter died from AIDS related causes. Her daughter was a single mother of two children, who were two and ten years old when she passed away, and thirteen and twenty one year old respectively at the time of data collection. The twenty one year old attends junior secondary while the thirteen years old was in primary school. Lesego's daughter was an airport employee and when she passed away, Lesego was paid some money by the airport authorities. The money helped the family to make ends meet, especially at the time when the orphans had not started receiving assistance from BOCP.

In 2005, Lesego lost a 28 year old granddaughter to AIDS who was a single mother of two children. The children were age three and four years old at the time she passed away. The care of these orphans fell on Lesego even though her daughter who is

the mother of her late granddaughter was alive and had a job. Lesego's daughter and granddaughter both died after a protracted illness and were cared for by Lesego until they passed away. She then continued to care for her orphaned grandchildren and great grandchildren. Since Lesego was getting frail and tired, she registered her two great grandchildren at the Kamogelo Daycare Centre so that she could relax when they were in school. Although two sources of income in Lesego's household were lost to AIDS as the moral and financial demands increased, Lesego's OAP helped to augment household income. Further, her adult children were also working and supporting the family.

After taking care of her own children, grandchildren, and great grandchildren, her adult children and grandchildren decided to take over all Lesego's responsibilities as she was getting very frail. Her twenty and twenty four year old grandchildren who had completed secondary school but were unemployed stepped in and were helping with household chores to enable Lesego to take a deserving break from care-giving responsibilities. Lesego's main activities at the time of data collection were limited to attending Kgotla (village or town hall) meetings, funerals, and church services.

### **Refilwe**

Refilwe was a 65 year old grandmother who lived with her 69 year old husband in a compound with four housing units and the main or family house. The family rented out the four houses and occupied the main house. The amenities available in these houses included electricity and water. Refilwe's husband was an auto mechanic but didn't make enough money from his job and so depended mainly on his OAP and rent from the houses. Refilwe also depended on OAP as she was not working out of the house.

In 1984, Refilwe's sister died from some unknown causes and left behind three children who were ten, twelve, and thirteen years old. A year later, the thirteen year old who had mental health problems also passed away. The two surviving children were cared for by Refilwe but moved into their late grandmother's house and lived on their own when they both became adults.

Refilwe and her husband had three children who lived with them until 2003 when one of them died from AIDS related diseases. At the time of the interview, Refilwe was caring for six people in her household. This included her husband, two adult children, one orphaned grandchild and another grandchild who was not an orphan. Refilwe's late daughter was a single mother who died after a protracted illness and left behind a 9-months old baby. At one point, both her husband and late daughter were admitted in the hospital and Refilwe was the only one caring for them. She thought that period was one of the most stressful times in her life as she had to care for two sick adults and her 9 months old grandchild. Refilwe believed that the stress might have contributed to her current ill health.

Refilwe suffered from hypertension and caring for her daughter and watching her die was stressful and emotionally difficult for her. Refilwe became emotional when discussing the effects of losing her daughter and care-giving burden on her health. Refilwe was on hypertension medication prescribed by her doctor which was refilled from time to time. When the stress started affecting her health, Refilwe's doctor advised her to stop worrying so much otherwise she could die of hypertension and the orphans would suffer as she was the only one who could care for them. Refilwe's emotional breakdown was regarded as indication that she was still grieving the death of her

daughter and had not fully dealt with the stressful emotions that came with the loss of her daughter.

Due to ill health, Refilwe did not work outside of the home. Her daily activities included performing household chores and caring for her grandchildren after school. Apart from Refilwe's ill health, she indicated that her family was doing well financially, as they received support from sources such as OAP, BOCP, rent, and adult children who were employed.

### **Banyana**

Banyana was a 73 year old widow who was on high blood pressure medication and lived in a compound with three housing units. One of the houses was rented out and the family occupied the others. The compound had running water but no electricity and firewood and gas were used for cooking and heating. Firewood was often used instead of gas because Banyana could not afford gas.

Banyana's husband died a long time ago and was survived by three children. Banyana took full responsibility of her family after the death of her husband. At the time of data collection, she was caring for ten family members in her household. This included two unemployed grandchildren (who were orphans until when they turn 18) who were nineteen and twenty five years old, two unmarried and unemployed adult sons (32 and 35 years old), three great grandchildren, granddaughter's unemployed boyfriend, and Banyana herself. One of her granddaughters got pregnant while still in school and later became pregnant again with a married man. The fathers of the two kids were not supporting them so Banyana had to provide for them and their unemployed mother. As

the burden of care-giving and providing for these children fell on Banyana's shoulders, she went to the social workers and explained her desperate situation to them. To her surprise, the three great grandchildren were registered with BOCP and Banyana received food baskets for her three great grandchildren although they were not orphans.

Banyana started caring for orphans in 2001 when her 36 year old daughter died of AIDS related causes, leaving behind two children age eight and fourteen years. Before her daughter passed away, Banyana was living in her own house with her two adult children. She moved in with her orphaned grandchildren after her daughter passed away and stayed with them for one year before moving back to her house with them. Banyana moved back because she could not afford to run two homes and did not have money to pay for her grandchildren's transportation to and from school. She put up her late daughter's house on rent and used the money to take care of the grandchildren.

The two orphaned grandchildren were both out of school and unemployed single mothers. The twenty-five year old had two young children and a boyfriend who was also unemployed and lived with her. They occupied one of the two-bedroom houses and depended on Banyana for food and most of their daily needs. The nineteen-year old dropped out of junior secondary school because of pregnancy, went back after giving birth but did not pass the exams and so could not continue with education. Although the orphans had grown up, Banyana was still taking care of them and their children (her great grandchildren). Banyana did not only care for her three great grandchildren but also cared for all the unemployed adults in her household.

With so many people to feed and limited income, Banyana registered her great grandchildren at the Kamogelo Daycare Centre, and obtained employment with the

Ipelegeng Program in order to make ends meet. She hoped to raise enough money from her job to build another house that would be put up for rent. Although Botswana has an unemployment rate of 17.8 percent (Central Statistics Office (CSO), 2012), it is interesting that old and frail Banyana was able to obtain employment but the five healthy unemployed youth in her household would do nothing but watch her work herself to death to feed them.

Banyana was not happy that one of her unemployed sons took some of the cement she bought to construct his own house rather than help her to build another family house. Her family depended on the monthly OAP she was receiving, the pay cheque from her job, BOCP, and money from the two rented houses. Banyana had a garden in her backyard where she cultivated maize and other vegetables to supplement food supply in her household. She also had a small chicken farm in her backyard where she spent most of her weekends and spare time. She sold some of the vegetables to members of her community while the family consumed the rest of it. Banyana performed house chores as well as shopped for the family at the end of each month as she knew where to buy cheap food items and those on sale in order to save money.

Banyana struggled with feeding her family because five members of her household were unemployed and depended on her OAP and the food baskets from BOCP that were meant for the orphans. To make matters worse, two of the orphans who were receiving assistance from BOCP turned eighteen and were kicked out of BOCP though they were unemployed. BOCP was another source of support Banyana lost, although her responsibilities continued to increase as the two orphans kicked out of BOCP depended on her for their daily needs. According to the interviewer's observation, Banyana looked



frail and tired probably due to nonstop care-giving responsibilities at an age where she needed care herself.

## **Mary**

Mary was an 87 year old widow who worked as a house maid until she retired. She had two adult children but one passed away in 1998. She had a sister who died before her daughter died in 1998. Mary's daughter was a single mother of seven children and lived in her own home with her children. Her compound was made of three detached houses with electricity and running water. The family used gas for cooking and heating. At the time of the interview, Mary lived with her five orphaned grandchildren who were all adults except the last child who was fifteen and still in school. A 32-year old employed cousin of the orphans also lived in Mary's household. Mary and the orphans lived in her late daughter's compound.

When Mary's daughter started a family as a single mother, she frequently cared for her grandchildren to enable her daughter to pursue her career and provide for her family. However, she stopped providing the childcare when her granddaughters were old enough to help her daughter with childcare. In 1998, Mary started caring for her orphaned grandchildren when her 43-year old daughter died of AIDS related causes. Her daughter left behind seven children but two of the children also died about year later. The first grandson died from a fatal car accident and the second grandson suddenly felt sick, was rushed to the hospital where he died a day later. This was a very stressful time for Mary especially because she lost her only sister just before all the misfortune started. It

appeared Mary was seriously affected by the death in her family as she frequently referred to them during the interview.

When Mary's daughter and the two eldest grandchildren passed away, she assumed the responsibility of caring for the five surviving grandchildren, who were one, nine, eleven, thirteen, and nineteen years old at the time of data collection. Given the ages of these orphans at the time of their mother's death, Mary moved in with them at the age of 73 to care for them. She acknowledged that caring for her one year old grandchild, who was HIV positive, was challenging. After Mary's daughter died, the one year old was always sick and needed to see the doctor often, which was not easy for Mary as she did not have the energy and money to take him to the clinic. However, with the financial and moral support of her niece and the availability of medication, Mary's grandson recovered and was doing well health wise. Mary's niece used to take the HIV infected child to see the doctor whenever he was sick as Mary was not able to carry the child to and from the hospital.

Mary's niece would sometimes buy groceries and prepare meals for the children when Mary was unable to cook because the child was sick. Mary used her monthly OAP and the food ration from the clinic to augment the food supply in her household while waiting for assistance from BOCP. When the orphans started receiving food baskets from BOCP the family's food and financial situation improved and became even better when Mary's grandchildren finished school and started working.

As the primary caregiver of five grandchildren, Mary was responsible for cooking, household chores, caring for the one year old by ensuring that he took his medication, and nurturing the orphans. Because it was difficult for Mary to care for her

HIV positive youngest grandson and at the same time performed household chores and cook for the family, the child was sent to a Daycare when he turned three years old. This decision provided Mary the opportunity to perform household chores and prepare meals for the family before the children returned home from school.

At the time of the interview, the youngest of the orphans was fifteen years old and attending junior secondary school while the other four had completed school and two of them were working and supporting their siblings and grandmother. The two grandchildren who were unemployed were looking for work while helping their grandmother with household chores and cooking.

Mary was excited that her 33 year old grandson would soon get married and prayed that God would let her see her great grandchildren before dying. As Mary's grandchildren grew up and became very responsible adults and supported each other and their grandmother, they decided to take control of all house activities that were performed by Mary as she lacked the physical and mental strength. However, Mary insisted on doing her own laundry against the will of her grandchildren because she was used to doing chores and wanted to keep herself busy.

Mary had high blood pressure but was not worried about her health condition; rather she was worried about her granddaughter who had completed secondary school and a diploma in Hospitality and Catering but was not interested in obtaining a job. Mary's granddaughter preferred sleeping and wandering around when others were at work. Mary pleaded with the interviewers to talk to her granddaughter about the importance of having a job at the end of the interview. She was on high blood pressure medication and Maringa tea. However, she noted she consults with the son of a man she

worked for as a house maid who was a medical doctor. When asked why she did not go public clinics for consultation, Mary noted that the doctor she consulted with has known her for long and treated her as he would his own mother, so she had no reason to go the public clinics for consultations. However, Mary noted that even though she did not visit public clinics, she believed the doctors there were great. Mary's activities were limited to doing her laundry, attending church services, weddings, and Kgotla (village or town hall) meetings.

#### **4.2 Participants' perspectives of care-giving**

In a study by Saengtienchai and Knodel (2001) on parental care-giving to adult children with AIDS, many of the participants admitted that although the care-giving period was very stressful for them, they undertook the role willingly and did not think of caring for their grandchildren as a burden but rather as parental responsibilities. Care is regarded as a cultural duty in Botswana and has cultural expectations, which are expressed and provided by kins either directly or indirectly to family members especially to the elderly, children, and other members of the community (Leininger & McFarland, 2006).

Throughout Sub-Saharan Africa, by necessity or voluntary contribution, older adults particularly women, play a vital role in combating AIDS and alleviating its impact on their families (WHO, 2002). In the Tswana culture, care-giving is a tradition of caring relationship in many families that has been handed down from generation to generation. According to Leininger and McFarland (2006), care-giving involves family members providing support to each other in times of illness, poverty, old age, education, careers,

and childcare and rearing. However, in order to get a better understanding of care-giving in the Tswana culture, the study explored participants' perspectives on care-giving and the findings were reported in this section.

All the participants viewed care-giving as a vital family responsibility that has always been the core of family support system in Botswana and elsewhere across Africa.

Mary confirmed this by stating that:

*When my late daughter started having children, I helped care for her first two children so caring for these children is just a continuation of what I did when she was alive. The only reason she did not want me to take care of her last born who was always sick is because she had older children who were helping her. I'm thankful to God that He kept me alive else these children would have been left by themselves after the death of their mother but because I'm here they at least have an adult to protect them.*

Monica, who lost two granddaughters to AIDS, thought that caring for her orphaned great grandchildren was a responsibility that any grandmother would not hesitate to take.

Monica summarised this as:

*It's my responsibility to support these children in any way possible because if they fail then my family has failed and with God's blessings I will continue to support them until when they are big enough to take of themselves.*

Mary's views were consistent with those of Ssengonzi (2007) who suggested that child fosterage was not a new phenomenon in Botswana and elsewhere in Africa, as grandparents and other elderly relatives traditionally have played a role in different forms in raising children within their extended family systems.

Some participants considered caring for their orphaned grandchildren as a way to maintain a continuous relationship with their deceased daughters or granddaughters. They considered caring for the orphans as a way of making their deceased daughters or granddaughters happy by doing what they would have done if they were alive. According

to Mpho, if her orphaned grandchildren were happy, her daughter would equally be happy. As she put it

*Caring for my grandchildren is a family duty and a means of connecting with my late daughter as they remind me of her. When my daughter was alive, her wish was to ensure that her children complete school and get good jobs so that they do not suffer like her. I want to make sure her dream for these children is achieved by making sure the children stay in school and by being there for them and rearing them the way my daughter would have done if she was alive.*

Rose's perspective on care-giving was similar to that of Mpho. According to Rose,

*This is my family and as a grandmother, it was my responsibility to be there for my grandchildren when their mother died. I have lived with these children and their late mother since they were born. My daughter and I cared for them until when she became sick and died. When she died the only way I could show my love for her was to continue caring and rearing her children properly. The first two months after her death were hell as the baby was always sick and it was difficult to feed the orphans but we managed with the OAP and now things are okay and the children are doing very well in health and in school.*

Furthermore; some participants believed that care-giving was protecting their families from failure or collapse. They thought sending their orphaned grandchildren to the orphanage would be tantamount to failure and to prevent this from happening, they had to step in and care for the orphans with or without resources. Mpho expressed this feeling when she said

*Caring for my grandkids is a blessing and comfort for me and I'm glad that my presence saved them from going to live in the orphanage, which would have been a disgrace to my family. Although we do not have much to eat in this house, it's better for these children than being in an orphanage. The children give me some closure and keep me accompany especially when I start thinking too much about my daughter. I will make my daughter proud by taking good care of these children and making sure that the kids do well in school.*

### 4.3 Stressors of older adult caregivers

The focus of this section was on the stressors of care-giving experienced by participants. The findings revealed that participants experienced challenges such as health issues, financial problems, food insecurity, and stigma and discrimination. To better understand the unique situation of each participant, a summary of the socio-demographic data and household composition of the participants was provided on Table 1 below.

Table 1: Socio-demographic data and household composition of the caregivers

Caregivers	Gender of deceased children	Year of death	Number of children at time of death	Caregivers' age at start of caregiving	Current age of caregivers	Number of orphans cared for	Total number of people cared for	Ages of orphans at time of death	Current age of orphans
Rose	Daughter	2000	3	53	65	3	6	2 days 8 9	12 20 21
Monica	Granddaughters	2009 2011	1 2	70 72	73	3	9	2 weeks 12 21	3 13 22
Neo	Daughters	1995 2000 2004	2 1 2	56 61 65	73	5	10	7 3 16 2 17	24 20 28 10 25
Mpho	Daughter	2011	3	68	68	3	4	6 10 14	6 10 14
Lesego	Daughter Granddaughter	2001 2005	2 2	71 75	82	4	9	2 10 3 4	13 21 10 11
Refilwe	Daughter	2003	1	56	65	1	6	9 months	9
Banyana	Daughter	2001	2	62	73	2	10	8 14	19 25
Mary	Daughter	1998	5	73	87	5	7	1 9 11 13 19	15 23 25 27 33

As shown on the table above, the year of death and caregivers' age at start of the care-giving provide information on how long they have cared for orphans. It also provided information on participants' ages, when they started care-giving and whether or not they were on OAP at the time or not. When this information was combined with the number of orphans cared for, orphans' ages, and the number of people in the household, a better picture of the participants' situation was illuminated.

#### 4.3.1 Health issues and healthcare services

With regard to health issues, the majority of the participants had health problems and the most common of them were and stress. Seven of the eight participants reported that they suffered from stress and hypertension. Mpho was the only participants who did not have any health issues though she noted that she was stressed by the death of her daughter and meeting the daily needs of the orphans. When asked if they thought these health issues were related to the death of their children and the care-giving burden, seven of them responded in the affirmative. Rose confirmed this when she said,

*I think it's because of too much thinking and worrying about the death of my daughter and caring for these little ones that I developed all these illnesses. I started caring for my youngest grandchild when he was just two days old and because I had no money and the baby was frequently sick, it was difficult for me to sleep at times as I was always thinking. This was the most stressful time in my life as not knowing what the kids would eat was a frequent occurrence until when I got assistance from BOCP."*

However, Mary had a different opinion about her ill health. She attributed the health challenges she was experiencing to old age rather than to the loss of her daughter and the care-giving burden. Mary noted that,

*When my daughter died, I was stressed and worried about her children especially the last born who was always sick and because I did not have the power (physical ability) and money at the time. But I do not think the stress was that serious to have affected my health. I think the illnesses I experienced are due to old age and not stress from the deaths in my family. I also have knees and lower back pain but I think all of these are caused by my age. Also, my grandchildren are hard working and very responsible kids who want me to be happy and not worry about anything as they now take very good care of me so they will not be happy to hear me complaining.*

Mary was happy about the fact that her older grandchildren have grown up to be very responsible and caring adults and probably thought linking her ill health to the burden of care-giving and the death of her daughter could give the impression that she was



suffering, and that her grandchildren were not taking good care of her. At the same time, Mary was probably right to say her ill health was due to old age and not stress because hypertension and lower back pain are common illnesses that many older adult caregivers suffer from.

Contrary to HelpAge International (2007) findings that older adult caregivers are discriminated against by healthcare workers and that accessing healthcare services was difficult for many older adults, this study found that caregivers had no complaints about the healthcare services they received and that they had easy access to free healthcare services. According to the findings of this study, clinics were located in most communities and services to older people and children were free. However, Rose and Mary who cared for HIV positive children were frequently referred to specialists in other parts of the city had different views about healthcare services. At the age of 73, Mary was frail and tired and had difficulties walking. She complained about the cost of transportation to and from specialists and her inability to take the sick child to specialists who were all out of her community. Mary questioned why these specialists could not come to community clinics to see the patients. According to Mary,

*If my niece did not help me, I don't know what I would have done with my grandchild. My niece used to take him to Marina hospital (a referral hospital) to see a specialist and because she knew I was tired, she would come and cook food for the children especially when the baby was sick.*

According to WHO (2002), caregivers seek treatment from traditional healers because of poor healthcare services and lack of money to pay for these services. On the contrary, this study found that older adult caregivers in Botswana had free healthcare services and that most communities had clinics nearby. The availability of free healthcare services explained why caregivers appeared to be happy with the quality of the healthcare

services they received and did not bother consulting traditional doctors. When asked about the quality and access to health care services, Rose said

*The clinic is not far from here but the problem I had when my youngest grandchild was sick was that he had to see a specialist in Gaborone and it was financially difficult for me when my daughter just died, as I did not have money to pay the bus fare. But when anybody else was sick they would visit the clinic over there.*

Mary had a private doctor not because the clinics were not good but because her grandchildren preferred that. Mary said,

*I see a private doctor and do not go to the public clinic for consultation. I have known this doctor since he was a child as I used to work in their house as a maid. Since he opened his own clinic, my grandchildren have always taken me to see him whenever I'm not feeling well. My grandchildren will then go to Marina (the main referral hospital) in Gaborone and collect the medication he prescribed for me.*

However, apart from Mary, Rose, Neo, Banyana, Monica, Lesego, and Refilwe believed that caring for their AIDS infected adult children or grandchildren until their death and subsequent care of the orphans contributed to the ill health they were experiencing at the time of data collection. This view expressed by Refilwe was shared by six other participants,

*Caring for my daughter and watching her die was very painful and the stress was intense when my daughter stopped talking and continued after her death. When I started suffering from hypertension, I was advised by my doctor to stop thinking too much and I decided to follow his advice because stress and hypertension could kill me and my family especially the orphans will suffer.*

Monica's views were similar to those of Refilwe and the other participants, but she put her views into perspective by indicating that,

*It is hard to stop thinking about my situation because I feel so hurt that it's difficult to express exactly I feel. Sometimes I try to forget but these sad feelings always come back when something happens to the orphan, my family, and when I can't meet family needs.*

### 4.3.2 Financial stressors and care-giving

The participants' financial challenges were also discussed during the interviews. The findings of the study revealed that, in addition to the health pressures, all participants except Refilwe, also experienced financial stressors. However, the severity of the financial stressors experienced by participants after the death of their adult child(ren) depended on the resources and options available to them at the time and whether the deceased was the family bread winner or not. Rose was one of the caregivers forced into poverty because she had little or no resources immediately after the death of her daughter as she quit her job to care for three orphaned grandchildren without any support. Rose said,

*Before my daughter became sick, we were both working and providing for the family. But because of her illness, she stopped working long before dying and when she became very sick and was also pregnant, I had to quit my job as well to care for her and my two grandchildren. The little money I had in my hands got finished so I decided to take her to my parent's house. When she died two days after giving birth, I buried her and moved back to my house with the orphans and no money at all as my parents treated me poorly. Caring for a few days old HIV positive baby and two orphans without money was scary and stressful. But by the Grace of God BOCP came to our rescue.*

May (2003) found that limited social programs and services for older adults contributed to poverty at old age and the findings of this study supported this assertion. For instance, participants with limited resources and support systems were pushed further into poverty before the intervention of BOCP. Those participants on OAP used it to provide for the needs of their families rather than personal needs.

Although four (Mpho, Lesego, Monica, and Mary) of the eight participants in this study depended on OAP as the main and reliable source of income immediately after the death of their adult children, it is worth noting that Neo, Banyana, Rose, and Refilwe

were 56, 62, 53, and 56 years old respectively when they started caring for orphans. Therefore, they were not eligible for the non-contributory OAP as the qualifying age in Botswana was 65+. Rose's household was forced into poverty while Refilwe's did not because she had other sources of income that Rose never had. Therefore, Rose was financially challenged and stressed while Refilwe was stressed but not financially challenged. Although Rose and Refilwe suffered from the same stressful life event and at a younger age than the others, their experiences and stress levels were different because of the resources and support systems available to them. Refilwe noted that the stress she experienced did not stem from financial issues but from the death of her daughter and the care-giving burden,

*When my daughter and my husband were admitted at the hospital at the same time, I cared for them and was scared that both of them would die. My husband got well but my daughter never made it. What stressed me was watching the person who would have taken care of me at old age die rather than the difficulty of caring for her child.*

Participants who took care of HIV positive orphans encountered more financial problems immediately after the death of their adult children as they had difficulties providing for the daily needs of their orphaned grandchildren and those of HIV positive orphans. For instance, Rose and Mary had to constantly feed the infected orphans on ARV as frequent hunger was one of the side effects of this medication. They also had to buy fruits and vegetables for the HIV positive children because these items were not included in the children's food baskets though needed to boost their immune systems. Further, the transportation cost of frequent visits to specialists was eating into the little money they had as explained by Rose,

*My grandson was not eating enough vegetables and fruits to keep his body healthy and because I did not have the money to buy fruits and vegetables for*

*him, the doctor gave me a list of fruits and vegetables that the child needed. I took the list to the social worker who added the items to the child's monthly food basket.*

Similar to Rose's views, Mary acknowledged the difficulties in caring for orphaned grandchildren as well as an HIV positive orphaned grandchild with limited resources. As Mary put it,

*Although I was on OAP when my daughter died, the money was not enough as I had to buy food for the kids and pay transportation to and from the specialist. I don't know what I would have done if BOCP did not give these children help because the one year old who was HIV positive was always sick and needed to see a specialist often.*

#### **4.3.3 Food insecurity and nutritional challenges**

According to the findings of this study, food insecurity was one of the major problems participants faced as caregivers of orphaned grandchildren. In households where the deceased was the main breadwinner or where the caregiver was the breadwinner but could no longer support the family because of care-giving responsibilities, poverty, and food shortages. Rose, Monica, Mpho, and Mary experienced serious food shortages immediately after the death of their adult children as their sources of income and support were either nonexistent or very limited. The limited resources made things difficult as many of the participants could not afford enough food to feed the orphans under their care. The participants who depended on OAP to feed their families experienced constant food shortages because the money meant to satisfy the needs of one individual was used to feed entire families. Mpho noted that,

*Since the death of my daughter, I have depended on OAP to pay rent and buy food for these kids and it has been very challenging for me as the orphans are not yet registered with BOCP though I have applied. I would have liked to have a small vegetable garden so that the harvest from the garden could be used to augment whatever my OAP can buy but I do not have the land.*

Although the participants found the assistance from BOCP helpful, it was often not enough to feed their entire families, which led to food insecurity in households especially if the food basket from BOCP was the only source of food and income for the household. For instance, orphans who turned 18 were no longer eligible for BOCP assistance though they depended on the caregiver and thus the food basket received by their younger siblings. This created shortage of food in households affected because most of these grown up orphans were either unemployed or still attending school. Rose was not happy that some of the orphans in her care were taken off BOCP when they turned 18 and said,

*The problem I have with BOCP is that since 2008, the food basket has drastically been reduced and because they take off orphans from the program when they turn 18, there is always food shortage in my household by month end as those off the program are unemployed and depend on the food basket of their siblings.*

Neo, Refilwe, and Lesego experienced less food insecurity in their households as they depended on a variety of resources and support that included: OAP, BOCP, farming, employed adult children, and rent from properties to meet the needs of the orphans and their entire families. Lesego said,

*Thank God that two of my children who are working are helping to buy food for the family and I'm also receiving OAP every month. The money we received from the airport where my late daughter was working and the food baskets from BOCP helped to buy food and other needs of the family. My children take care of the cattle and goats that we own and this also helps on rainy days. Things have been very difficult but God has also intervened and I can't complain much.*

#### **4.3.4 Stigma and discrimination of caregivers**

The findings also revealed that seven of the eight caregivers who participated in the study did not personally experience stigma and discrimination even though they have heard of instances where people discriminated against caregivers of AIDS patients, AIDS patients, and AIDS orphans. On two occasions, Rose said she was discriminated against

because of the HIV status of her grandson and her late daughter. What hurt her feelings the most was when her own parents and siblings treated her and her sick daughter as outcasts. As Rose put it,

*When my family rejected my daughter, I felt terrible inside but had to pull myself together and give my daughter the best care. I thought of returning with my daughter to my house but did not have any money on me so I had to endure the rejection until she passed away. My parents and siblings refused to eat food cooked by me and would not touch my daughter. As the newborn baby was also HIV positive, I had to move back to my house as soon as my daughter was buried though not sure how I was going to feed the kids.*

When Rose's HIV positive orphaned grandson was ready to enter primary school, she went looking for a school and thought some school authorities discriminated against her grandson because of his HIV status. She explained her experience this way,

*When I visited one public school to get my grandson registered, I was made to understand that there was space available until when I told the lady I met at the school that my grandson was on medication (i.e. ARV) and that he would have to be fed when he was quiet and not play with others as that would indicate hunger. When I finished giving her this information about the child, she told me the class was full so he could not be admitted. I was upset but said to myself well; I must not blame this lady because even my own family rejected my sick daughter because of her status. So I went to different public school and my grandson was given admission though I decided not to tell them anything about the child's status.*

#### **4.4 Coping strategies of older adult caregivers**

In this section, the strategies adopted by the participants to cope with the stressors of care-giving are presented. The findings of the study revealed that participants used different strategies to deal with the stressors they faced. According to the findings, the coping strategies adopted by the participants included prescribed medications, rents from property, starting small businesses, depending on farming, OAP, BOCP, support from

family members, and obtaining employment. The different coping strategies adopted by caregivers are summarized on Table 2.

Table 2: Caregivers' sources of income and food supply before and after the death of adult child (ren)

Caregivers	Age of caregivers	Sources of support before death	Sources of support after death
Rose	65	Participant working Daughter working School feeding	BOCP Food rations from clinics Daughters working Small business School feeding House rent
Monica	73	Subsistence farming OAP Adult children working School feeding	Farming Caregiver's pay cheque OAP Food rations from clinics School feeding BOCP Adult children working
Neo	73	Live stock farming Adult children working OAP School feeding	OAP School feeding Land compensation Farming BOCP Food rations from clinics
Mpho	68	OAP Daughter working	OAP School feeding
Lesego	82	Livestock farming Adult children working OAP School feeding	BOCP Adult children working Benefits from deceased child's employer OAP Food rations from clinics School feeding Farming
Refilwe	65	Adult children working House rent	House rent Adult children working Spouse on OAP BOCP OAP School feeding
Banyana	73	House rent Chicken & vegetable farm Adult children working OAP School feeding	Caregiver's pay cheque BOCP House rent Subsistence & chicken farming Adult children working OAP School feeding
Mary	87	OAP Adult child working School feeding	BOCP School feeding Food rations from clinics OAP Grandchildren working Financial support from relatives

The Caregivers' sources of income and food supply before and after the death of adult child (ren) as shown on Table 2, summarizes the financial and food situation of the participants and enables the reader to understand how the participants dealt with the food and financial challenges they faced.



#### 4.4.1 Coping with health and healthcare issues

The most common health challenges the participants experienced were stress and hypertension. Considering that healthcare services for seniors, children, and pregnant women in Botswana were free, the participants and the orphans in their care were entitled to free healthcare services and medications which is a rare occurrence in many African countries. This finding is contrary to the findings of HelpAge International (2007), which indicated that limited access to healthcare services especially in the rural areas was one of the major problems caregivers of AIDS orphans faced. HelpAge International (2007) concluded that some older adult caregivers sold personal or family property or used past savings to pay for healthcare services and medications and those who could not afford the cost of healthcare, turned to traditional doctors for treatment. According to this study, the poorest participant had access to free healthcare services with clinics located within walking distances in most communities in Botswana. All the seven participants who reported ill health were on prescribed medications which were further supported by prayers. Some of them also took Maringa tea to keep their stress levels in check but the tea was a personal intervention that the participants adopted and it should be noted that the tea was not given to them by traditional doctors. As Rose stated,

*I take the medication that my doctor prescribed and also take Maringa tea as it helps with hypertension and stress. I pray to God every day that He should continue to take care of my situation as he has always done. I have placed everything in His hands.*

Rose also adopted personal strategies to cope with the stress of losing an adult child and caring for three orphaned grandchildren with limited resources. Rose said,

*I tried not to be lonely so that I do not keep thinking about my situation. That is why I keep myself busy by cleaning the house or focusing on my business when*

*there is no one to talk to. I also tell my story to people who are willing to give me a listening ear and this at times helps to reduce the stress I feel.*

Monica suffered from stress and high blood pressure. She reported that she was on prescribed medication for high blood pressure and also used Maringa tea to reduce stress levels. Maringa tea appeared to be a popular herb among caregivers with stress and anxiety. In addition to the medication, Monica said,

*The death of my granddaughters and the stress of care-giving were affecting me so much and one Reverent Sister decided to help me by coming and counselling me in my house when she had the time. The counselling and medicine were working as my stress level has reduced a lot.*

Of the seven participants who reported ill health, Monica was the only one who received counselling. It is likely that most of the participants were overwhelmed by the challenges of care-giving and the trauma of losing an adult child but they never had the chance to grieve the loss of their children. The lack of access to counselling services may explain why many of the participants were still grieving after so many years. However, Neo coped with health challenges by taking prescribed medication and praying for healing and intervention from God.

#### **4.4.2 Coping with financial stressors**

The study also explored the participants' strategies to deal with the financial stressors they faced as caregivers. The findings revealed that the participants experienced financial challenges that affected other aspects of their lives, such as food supply in their households and the proper execution of their care-giving duties. Before BOCP intervention, Rose, Mary and Mpho could barely afford food and transportation to clinics, especially those who were caring for frequently ill HIV positive orphans. To cope with

these stressors, participants adopted coping strategies, which included using OAP, relying on adult children and relatives, BOCP, taking up employment, starting small businesses, farming activities, and money from rented properties.

OAP was one of the first financial interventions that some participants turned to in order to cope with the loss of income and apparent poverty after the death of a breadwinner in their families. Mary, Lesego, Monica, and Mpho who were receiving OAP before the death of their child or children continued to rely on it while waiting for assistance from BOCP. Of the eight participants in this study, Mary, Rose, and Mpho acknowledged that OAP was their only source of income immediately after the death of their daughters and breadwinners. Mary said,

*When my daughter passed away after a protracted illness, I was left with her five children and no money as all the money she had was used for her treatment. Because the orphans were still young and in school the only source of income I had at the time was my OAP, which was used in buying food for the entire household. Although sometimes my niece used to help buy groceries for the kids, it was difficult for me and the kids to live on the OAP that I was getting every month.*

Mpho's case was more challenging because unlike the other participants who lived in their own homes; she lived on a rented piece of land where her shack was erected. She applied to register her orphaned grandchildren with BOCP as she was paying rent (P90.00) on the piece of land on which she built the shack as well as buying food for her family from the P220.00 monthly OAP she was receiving from the government. At the time of data collection, the hardship faced by Mpho's family was apparent but she was hoping and praying for help from BOCP and the Gaborone City Council (GCC) where she applied for a low cost house. Mpho summarised her situation as,

*It has been hard for me to pay rent and feed the kids with the OAP I receive and because of lack of childcare; I have not been able to obtain employment. I'm*

*praying that BOCP would start helping soon so that there can be enough food in the house for these children. I'm also hoping and praying that GCC would give me a small house so I can take the children out of this hut.*

BOCP assisted registered orphans in Botswana by providing them with monthly food baskets, a P500.00 allowance for each orphan, and all the school needs of the orphans attending school. BOCP and OAP were the main source of income for most of the participants in this study. Seven of the eight participants were receiving food and financial assistance from BOCP; however, due to the 2008 collapse of the world economy and an increase in the number of BOCP recipients, the quantity of food and the amount of money given to orphans as food baskets was reduced. As Rose noted,

*When my grandkids started receiving the food baskets from BOCP it was accompanied by P800 but in 2008, the amount was reduced to P500 and the quantity of the food basket also reduced. But I'm glad I was able to start this small business before these changes as the profit from the business sometimes helps to buy food at the end of the month when food shortages are rampant.*

As soon as Rose's teenage girls turned eighteen and started working, they were able to support the family financially. When the youngest orphan was old enough to start school, Rose could not look for employment because of ill health. In order to raise money and keep herself busy, she started a small business in front of her house by selling candies, chibuku (local beer), and cigarettes.

Monica and Banyana registered the youngest orphans in their care in a Daycare when they were old enough and obtained employment with the hope of raising money for their families. Banyana said,

*I obtained employment because I wanted to build another small house and put it on rent and the money would be used to augment household income and buy necessities for the family. But what makes me angry is the fact that one of my sons will not let this happen as he took the cement I bought and was constructing his own house with it.*

Although she was caring for an HIV positive child, Rose had to work menial jobs to buy food for her family, as she had no other source of income immediately after the death of her daughter. Rose noted,

*I used to go around my neighborhood with the baby on my back looking for piece jobs when my older grandchildren left for school and whatever money I could raise was used to buy food for the children. But thank God BOCP intervened and the orphans started receiving food baskets.*

Financial contributions from adult children, relatives, and rented property were a valuable source of support to several participants and the orphans. Monica, Lesego, Banyana, Refilwe, and Mary received financial and moral support from their adult children and relatives before and after BOCP interventions. When Refilwe's daughter died, she was not eligible for OAP at the time and therefore, depended very much on the financial support of her two adult children who were employed as well as on the income she received from rented property. Refilwe said,

*After the death of my daughter, I was stressed and worried about caring for my 9 months old grandchild without my daughter's support. I was not worried about money because my children were working and supporting me and the orphan and we also collected rent from the houses. With the support of BOCP, I really can't complain about money or food.*

#### **4.4.3 Coping with household food insecurity and nutritional issues**

The participants discussed the different strategies they adopted in order to cope with food shortages and food insecurity in their households. The data revealed that those who depended on OAP as their main source of income, found it more difficult to meet the food and nutritional needs of their families than those with many sources of income. To feed themselves and the orphans, the participants used food rations from the clinic, subsistence farming and gardening, OAP, BOCP, and income from adult children and

relatives. The monthly food ration from clinics was provided to all children between the ages of 0-5 years in Botswana and while waiting for assistance from BOCP, participants caring for children who were five years old or less depended on the food rations from the clinic. The food ration from the clinic was the only major source of food Rose had immediately after her daughter's death. Rose said *"I had to get out and look for a piece job while waiting for assistance from BOCP because the food ration the baby was getting from the clinic was not enough to feed my entire family."*

Rose started a small business as a way of coping with food shortages and financial problems especially towards the end of the month. According to Rose

*When I got money from BOCP, I decided to use some of it to start a small business. So I started selling things like cigarettes, matches/lighters, candies, and chibuku (a local beer made from sorghum) in front of my house. This has kept me busy and also put some money in my pocket.*

The food baskets that participants received did not include rice and chicken but some participants bought these food items in order to avoid monotony in their diet or meals. As Rose indicated, *"I'm grateful to God that these children are not choosy and would eat whatever is available without complaining. But sometimes I buy rice and chicken for them at the end of the month just to change things a bit."*

As shown on Table 2, the food basket from BOCP was the main and most reliable source of food supply for many participants and their families. Most of them indicated that after the death of their adult children, the assistance they received from BOCP protected their families from hunger and abject poverty. Mary confirmed this view when she said,

*Although I was on OAP when my daughter passed away, it could not sustain a family of six especially because the baby was always sick and required frequent visits to the hospital. There were days that if my niece did not buy groceries the*

*kids would have had nothing to eat. The four food baskets from BOCP that was accompanied with P500.00 each (i.e. P500x4 = P2000.00 total) every month were very helpful as the children had enough food to eat. Although only one orphan is receiving assistance from BOCP at the moment, two of my older grandchildren are working and supporting the family.*

The assistance provided by adult children and relatives played a vital role in dealing with poverty and food insecurity in some households. For instance, Lesego, Refilwe, Banyana, and Mary depended on their adult children and relatives during difficult times especially before BOCP's intervention. Mary explained that,

*When my daughter just died, things were tough and my niece would sometimes buy groceries for the kids when there was no food in the house and when the baby was sick and I could not cook because I did not have the energy to care for a sick child and cook, she would come and cook for the kids.*

Noe, Lesego, Banyana, and Monica used livestock and subsistence farming to augment the food supply and improve the financial situation in their households. Neo and Lesego reared cattle and goats, Monica had a vegetable garden and a small chicken farm, and Neo ploughed crops such as maize, potatoes and other vegetables. Neo said, “Although the family depends on financial support from my adult children who are working and the farm, BOCP has also assisted the orphans a lot by providing them with food baskets, some spending money, and all their school needs.” Monica also used subsistence farming and a vegetable garden in her backyard to cope with the month end food shortages in her household. As she put it,

*I stopped ploughing the fields because of poor rainfall and got a job at the Daycare Centre but I still grow vegetables in my backyard and rear chickens, which have been very helpful in augmenting household food supply towards month end when we frequently run out of food.*

#### **4.4.4 Coping with stigma and discrimination challenges**

Rose experienced stigma and discrimination from her family and dealt with it by leaving her parents' home and returning to hers though she had no money with her. Rose said,

*I was surprised and upset with my parents and siblings for treating me and my daughter as outcasts. So when my daughter died and was buried, I came back to my house with the new born baby though I did not have money on me. I suffered a lot to feed the kids but thank God we got support from BOCP.*

Contrary to the WHO (2002) findings, only one of the eight participants in this study experienced stigma and discrimination, which was an indication that stigma and discrimination may exist in the participants' communities but it was not a major problem. Although seven of the participants had not experienced stigma and discrimination per say, they took precautions to prevent it from happening to them. For instance, Mpho socialized only with those who have had similar experiences to ensure that people did not judge or discriminate against her. She said,

*I have not experienced discrimination because I have one friend that I socialize with who has lost a child to AIDS also. I avoid people who may judge me or discriminate against me because of what happened to my daughter – so I socialized with people who understand what it means to lose a child to AIDS.*

Neo used isolation and prayers as a secret weapon against stigma. She indicated that she prayed to God for help and kept to herself when she said,

*I kept my daughter's illness to myself and did not go to places where people will ask me about it. I asked myself so many questions without answers and because it was stressing me so much I decided to stop worrying and put everything in the hands of God.*

#### **4.5 New themes identified from the data**

Based on the data collected and analyzed, new themes were identified and presented to provide a better understanding of the study findings. The new themes



identified were school feeding and school fees food shortages and lack of variety, and gender and care-giving.

#### **4.5.1 School feeding and school fees**

According to this study, Botswana provided two meals to all students attending both primary and secondary public schools on school days. Children, especially those that would otherwise have gone hungry at home, stayed in school because they received free food and education. All the participants acknowledged the fact that school feeding kept children in school and helped them cope with food shortages in their households as they provided the children with only one meal on weekdays instead of three. Like the other participants, Mary noted said

*After the death of my daughter, the OAP I was receiving was too small to buy food for my five grandchildren but because they were eating in school the challenge I faced was providing them with food after school. When the children started getting support from BOCP, things improved.*

However, WHO (2002) found that orphans dropped out of school due to hunger or were removed from school by their caregivers so they could obtain employment and support their families financially.

#### **4.5.2 Food shortages and lack of variety**

During the interviews, the participants frequently brought up the issue of food shortages and lack of variety as one of the challenges they faced. Seven of the eight participants interviewed indicated experiencing shortage of food in their households. However, some of the participants were a bit confused between shortage of food and lack of variety as what Monica, Lesego, and Banyana considered to be scarcity of food was

lack of variety in the food items in their households. For instance, a lack of maize meal (staple food in Botswana) in their household was considered as shortage of food rather than lack of variety though they had other food items such as rice and pasta.

Refilwe never had any issues regarding food but Mpho, Neo, Rose, and Mary experienced scarcity of food in their households as they were either caring for non orphans who were not on BOCP or unemployed adult children. All the orphans on BOCP assistance were given both food and money (P500.00) monthly although shortage of food among caregivers was a common problem. Caregivers did not understand that the P500.00 given to each orphan with the food basket was for the purchase other food items that were not included in the food basket in order to avoid diet monotony and food shortages. Therefore, when the participants used the money meant for food and basic needs of the orphans in building houses or in feeding the unemployed adults, there is bound to be shortage of food and lack of variety in their households.

Although Banyana's orphaned grandchildren were no longer on BOCP assistance as the youngest was eighteen years old at the time of data collection, she alluded to her past experiences with food shortages when she said "*I decided to look for work because the food baskets was not enough and would run out before month end.*" Neo also experienced food shortages especially because she had five unemployed adults in her household who depended on BOCP assistance and the farm for their daily needs.

#### **4.5.3 Gender and care-giving**

Although men perform care-giving tasks, the primary caregivers in most families are usually females. Societal norms worldwide tend to assign reproductive labor, such as

childcare, caring for the sick and the elderly, cooking, cleaning and performing other household activities to women while men work mainly outside of the home as the main breadwinners of their households (Kes & Swaminathan, 2006). The Tswana culture practice gendered division of labour which has been replicated in the context of HIV/AIDS in Botswana. With high HIV/AIDS infection and death rate in Botswana, the government introduced the Community Home-Base Care Program in 1990 as a strategy of sharing care-giving burden between hospitals and families. With this program in place, some of the terminally ill AIDS patients were discharged from hospitals and sent home where most of the care was then provided by family members. The care of these terminally ill people felt on the shoulders of women as in the Tswana culture they are the main caregivers in their households.

In many African cultures, women are the custodians of their families as they are responsible for subsistence crop cultivation and the well being of their families while the men provide moral and financial support to their families by working outside of the home. Women perform activities such as childcare and rearing, ploughing the farm, caring for the sick and the elderly, performing household chores and feeding their families. According to Kipp, Tindyebwa, Karamagi, & Rubaale (2007) women are already overburden with the responsibilities for the general health of their families, household food security, children's welfare and education, and for managing scarce resources. At an older age, women hand over these responsibilities to younger women and the cultural norms are then passed down from generation to generation.

The effect of HIV/AIDS on women in Botswana was highlighted in this study by the fact that all the participants were women and all their adult children and

grandchildren who died of AIDS were single women. As illustrated on Table 1 above, the study found that with the onset of HIV/AIDS, more young women than men died from AIDS related causes and frail elderly women continue to perform care-giving responsibilities instead of retiring and receiving care from young female family members as the culture demands. These findings concur with the results of a report by UNAIDS (2010) on global HIV/AIDS that 11.3 million people in Southern Africa were living with HIV in 2009 and that about 40 percent of them were adult women.

#### **4.6 Suggestions from participants**

Refilwe, Lesego, Neo, and Mary had no suggestions to offer while Banyana, Rose, Mpho, and Monica discussed steps that could be taken to improve the quality of the care provided to the orphans. The four participants who offered suggestions focused mainly on how BOCP could improve or change some of its policies and increasing OAP. Rose suggested that BOCP should consider increasing the quantity of food items in the food baskets as she thought the food basket was not enough to sustain the orphans for the entire month. The study found that those participants who did not offer suggestions for improvement, had other reliable sources of support and were using the food basket from BOCP to augment what they receive from other sources.

The orphans who were over eighteen years of age and unemployed depended on the food basket given to their siblings and this created food shortages in many households. Rose suggested that

*In order to avoid the constant food shortages at month end, BOCP should continue giving orphans the food basket when they turn 18 and are unemployed or still in school until when they complete school or pick up an employment.*

Further, Rose indicated,

*BOCP should increase the quantity of the food basket. We used to get P800 per orphan and enough food for the month but this changed as the quantity of the food and the amount of money given to orphans reduced. What we get now is small compared to what we were getting before 2008 and I think this is also contributing to the frequent food shortages in my household.*

Banyana and Monica shared Rose's suggestion that BOCP should increase the quantity of the food basket and allow orphans who turned eighteen to remain on the program until when they picked up a job. In addition, they thought the government should review and increase OAP as the prices of food stuff and other commodities continue to rise and also because more and more family members depend on OAP.

Monica suggested that

*Although the government is really helping, the food baskets are not enough and should be increased. I think the government should look at the situation of old people again and increase OAP as the prices had gone up and many family members depend on seniors and the OAP they receive. If BOCP food baskets and OAP are increased, I will be able to meet the needs of the orphans and live a better life without working to make ends meet. I also think with the help of NGOs the government will be able to do all what I'm talking about.*

Mpho's daughter died in 2011 and she applied to register her three orphaned grandchildren with BOCP and has been waiting for a response from BOCP for more than three months at the time of data collection. She was not happy about this delay as her family depended solely on her monthly OAP and the interviewers observed that Mpho's situation required urgent assistance. Mpho suggested that *"The government should make the registration process faster so that those who need and qualify for BOCP assistance do not wait for so long before getting the assistance."*

## CHAPTER 5

### DISCUSSION, CONCLUSION, RECOMMENDATIONS, AND SUGGESTIONS FOR FURTHER RESEARCH

The purpose of this study was to explore the stressors and coping strategies of older adult caregivers in Botswana who have previously cared for or were caring for AIDS orphans at the time of the study. The findings of this study revealed that caregivers who themselves needed care were subjected to different care-giving stressors arising from ill health, financial problems, food and nutritional issues and stigmatisation and discrimination as discussed subsequently. Participants' perspectives of care-giving and suggestions on what could be done to facilitate their ability to effectively carry out care-giving responsibilities are also discussed in this section. This chapter further discusses the findings of the study in relation to the literature reviewed, provides recommendations arising from the findings, and offers suggestions for further research

#### 5.1 Participants' perspectives of care-giving

Care-giving was viewed by participants as a cultural norm in the Tswana culture that has been handed down from generation to generation and required family members to care for each other especially in times of need. The participants viewed care-giving as a family responsibility that must be performed to prevent the family from failing by fighting adversity with a united force. Neo argued in favour of this by saying "*This is my family and it is my responsibility to support my grandchildren and to protect them at all times.*"

Before the onset of HIV/AIDS, sending a family member to the orphanage was stigmatized and regarded as failure or an indication of family dysfunction in the Tswana culture as argued by participants. Therefore, the care of orphaned and vulnerable children

by their relatives was culturally encouraged and supported by social policies and programs. For example, one of the goals of BOCP was to encourage family members to care for the orphans in their families and in order to reduce the burden of care-giving on caregivers, orphans were provided with food and financial support and all their school needs taken care of. In support of the above argument, Testa and Rolock (1999) stated that Kinship care is the full time nurturing and protection of children separated from their parents by relatives, members of their tribes, clans, godparents, stepparents or other adults who have a kinship bond with a child.

According Banyana, orphans should remain in their families as sending them to the orphanage after the death of their parent (s) increases their stresses levels even more because they are cared for by people they do not know and may not really have their interest at heart as their family members would. Testa and Rolock (1999) argue in favour of kinship care by stating that, placing children with people they know and are familiar with, lessens the possibility of depression and isolation that are consequences of separation, and offers growth and development within the context of a child's culture and community. In the same vein, despite the difficulties, the extended family safety net was still the most effective response to economic and social crisis throughout sub-Saharan Africa where an estimated 90 percent of orphaned children live with extended family members including aunts, uncles, grandparents, and other relatives (Miller, Gruskin, Subramanian, Rajaraman, & Heymann, 2006). They further argued that the tradition of fostering by extended families continues today and is a vital coping mechanism in nations like Botswana with high HIV prevalence rate and growing orphan populations.

## **5.2 Stressors of older adults as caregivers**

Before the onset of HIV/AIDS, care-giving in the Tswana culture was mainly done by young people who had the mental and physical abilities to deal with the emotional and physical challenges that accompanied care-giving. All of the participants in this study have taken care of grandchildren at some point in their life time and at old age when they themselves needed care; they take on care-giving responsibilities again. For instance, grandparents and parents provide childcare when their adult children start families as single parents, when grandchildren are unmarried teenage mothers, and when young adults with children are perusing careers or further education. However, many older adults are now surviving their adult children and becoming sole caregivers of their orphaned grand and great grandchildren. By taking on the care-giving role as primary caregivers, older adults in this study faced health and financial problems as well as food shortages and stigmatization as discussed subsequently.

### **5.2.1 Health issues and healthcare services**

Care-giving requires both mental and physical abilities to cope with its challenges and becoming a caregiver at an older age compromised the health of six participants in this study. The participants alluded to the sadness, stress, hypertension, and the anxiety they experienced after losing a breadwinner or an adult child who was providing and would have cared for them at an old age. Consistent with the health issues experienced by participants in this study, Hughes et al. (2007) found that grandmothers caring for grandchildren in skipped-generation households would experience health declines, but



grandmothers who babysit grandchildren in an adult child`s household may experience health benefits.

The feelings of stress and sadness that led to health decline in the participants were further intensified by the challenges of caring for an HIV positive child as they required more attention than their frail and old caregivers could provide. Mary supported this by arguing that “*When my daughter died, I was stressed and worried about her children especially the last born who was always sick and because I did not have the power (physical ability) and money at the time.*” This study found that caring for an HIV positive child had a negative effect on the health of caregivers as these children were often ill and required more attention than their old and frail caregivers could provide. In support of the argument, Ssengonzi’s (2007) concurred that older adult caregivers reported experiencing more health problems, stress, and financial problems over the burden of fostering orphaned grand and great grandchildren. Given the intense stress and continuous grief experienced by caregivers, a lack of counselling and other stress management intervention programs contributed to the hypertension that seven of the eight participants experienced and the stress that all of them reported experiencing.

Although healthcare services for seniors and children in Botswana were free and clinics were located at walking distances in most communities, the healthcare services failed to focus on the mental health of the caregivers as revealed by the findings of the study. Although participants were not able to grieve the death of their adult children because they were overwhelmed with the burden of care-giving, healthcare professionals and BOCP failed to focus on participants’ emotional wellbeing through counselling and exercise programs. For instance, only one of the eight participants in the study reported

receiving professional counselling and the rest of them prayed or did nothing about the intense stress and anxiety they experienced. The study found that because the stressful emotions experienced by participants were not dealt with, most of the participants had not gone through the grieving process since the death of their children. As an indication that some of the participants were still grieving, Refilwe, Rose, Monica, Lesego, and Banyana, became emotional and tearful during the interviews especially when discussing the effects of losing an adult child and becoming the primary caregivers for their orphaned grandchildren on their health and finances.

Considering that care-giving is stressful and physically demanding, performing care-giving responsibilities for a prolonged period of time had negative health consequences such as hypertension stress, and depression on older adult caregivers especially those who cared for AIDS infected adult children, orphaned grandchildren, and great grandchildren. Monica cared for her two children, three granddaughters, and AIDS infected granddaughters and her orphaned great grandchildren at a frail age with limited resources and mental and physical abilities. At the age of 70, Monica became the primary caregiver of a two weeks old AIDS orphaned grandchild and obtained employment at the age of 73 to enable her meet the daily needs of her family. With a life-time of childcare and rearing, it was no surprise that Monica reported suffering from stress and hypertension. Goodman and Silverstein (2005) support this in a study on Latina grandmothers raising grandchildren by arguing that grandparent caregivers with extensive caring hours reported more depressive symptoms and less life satisfaction than grandparent non-caregivers do.

### **5.2.2 Financial stressors and care-giving**

Financial challenges were a common stressor expressed by all the participants although each of them dealt with these stressors in their own unique way. Some of the financial challenges experienced by the participants were lack of transportation fair for school children and for HIV positive orphans who frequently visited specialists, as well as lack of money to buy food and meet other daily needs of their households. However, the extent of the immediate financial stressors experienced by the participants after the death of their child (ren), was greatly influenced by the resources and support (family and social programs) available to them. For instance, before the intervention of BOCP, those who had financial support from family members, OAP, employment, and farming experienced less financial stress than those who lacked these sources of support as concurred by HelpAge Zimbabwe (2002b).

Mary, Rose, and Mpho were pushed even further into poverty immediately after the death of their adult children due to limited resources and support. However, those with resources and support experienced fewer financial drawbacks which were not severe enough to force them into poverty. Therefore, participants' stress levels were influenced by the support and resources available to them. For example, when Rose and Refilwe lost their daughters to AIDS, they were both not eligible for OAP at the time and they did not work outside of the home as they were caring for orphans who were less than a year old. Rose had no source of support (e.g. past savings and income from adult children or relatives) to depend on while Refilwe received support from her adult children and income from rented property and therefore, was less stressed than Rose. This finding is consistent with the Stress, Appraisal, and Coping Theory of Lazarus and Folkman (1984)

that was adopted and used in this study. According to the theory, what leads to dysfunction or stress is usually not the problem or the stressful event; but rather it is the individual's appraisal of the severity of the problem that may lead to the stress experienced and the action taken to deal with the stressor.

The poverty experienced immediately after the death of an adult child was one of the main problems the participants reported as they could not afford the basic needs of their families. Although primary and secondary education in Botswana was free and two meals were provided to all students, Parents and guardians are expected to provide the basic school needs (e.g. transportation to school, pens/pencils, and uniforms) of their children. Due to financial problems, Mary, Banyana, Rose, Mpho and Monica could not afford the school needs of orphans as they were struggling financially. In the same vein, a study by WHO (2002) supports the fact that participants faced financial problems and could not afford school fees and other basic school needs of the orphans.

### **5.2.3 Food insecurity challenges and care-giving**

The findings of this study suggest that food insecurity in participants' households remained a major challenge despite the intervention from BOCP. The food insecurity in participants' households was influenced by the resources and support systems available to them. For example, Rose's main and only source of food was assistance from BOCP and she reported experiencing a general lack of food supply by the end of each month. The assistance from BOCP would have been enough for Rose and the orphans to live relatively comfortably if Rose's two daughters never depended on it. However, the food

shortage in Neo's household was caused by the five unemployed adults who depended on the food baskets meant for the orphans.

In spite of the above mentioned problems, the participants in this study were on average better off financially and socially than their counterparts in other African countries. One of the factors that contributed to this difference between caregivers in Botswana and in most African countries was the social-economic policies of the Government of Botswana that focused on the welfare of the poor, children, and seniors. For instance, social welfare programs such as BOCP, Destitute Program, OAP, school feeding program, free education, food rations from clinics for 0-5 year old children, and free healthcare services for seniors, pregnant women, and children are some of the programs geared towards alleviating poverty in the country.

Although other African countries such as Mauritius, Lesotho (have universal pension schemes), South Africa, and Namibia (have a means tested pension scheme), most of the social programs (e.g. school feeding and free education and healthcare services) provided in Botswana are lacking in many of these countries where AIDS orphans and vulnerable children are withdrawn from school due to lack of school fees and eat less due to shortage of food. WHO (2002) found that caregivers of AIDS orphans turned to traditional doctors for treatment and bought cheap food items due to poverty and a general lack of social programs such as OAP and free healthcare services.

The study also found that Mary and Rose who cared for HIV positive orphans experienced more food problems than those not caring for HIV positive orphans. Considering that one of the side effects of ARV is increase in appetite, HIV positive orphans who were on ARV ate frequently and required special diets, fruits, and

vegetables to build and maintain a strong immune system. Although the maize meal and other food items in the BOCP food baskets were nutritious and contained multi vitamins, they were not nutritious enough to boost the immune systems of the orphans who were on ARV. Therefore, caregivers of HIV positive orphans either requested BOCP to add fruit and vegetables to the food basket of these orphans or bought the required food items needed themselves.

#### **5.2.4 Stigma and discrimination**

Losing an adult child at old age especially to a stigmatized disease such AIDS, for most or all of the participants was heartbreaking and these feelings were further intensified by fears of stigmatization from friends and family members. For this reason, some of the participants never wanted to socialize with their peers or community members either because they were overwhelmed with the burden of care-giving or because they wanted to avoid being stigmatized and discriminated against by people. For instance, Mpho socialized only with people who have had similar experiences and Monica kept the illness of her late daughter and granddaughter to herself. This was consistent with Hayslip and Kaminski (2005) findings that grandparent caregivers were likely to be isolated from their age peers because of stigma, care-giving burden, and stress.

The misconceptions and the myth attached to HIV/AIDS, created the stigma and discrimination that was a key contributing factor in the spread of HIV in Botswana. In 1997, the focus on HIV/AIDS in Botswana was directed to educating the public on HIV/AIDS as the misinformation and myth about the disease contributed to stigma and

discrimination and prevented those infected from obtaining required treatment and services. As a prevention strategy, young people and adults were educated through targeted radio and television programs, art, and plays in Botswana. Through mass media, the general public was provided with accurate information on the disease and this awareness greatly reduced the problem of stigma and discrimination. The awareness further increased the number of people willing to request for treatment or take the HIV test to know their status as such reduced the number of new infections and AIDS related death rate.

### **5.3 Coping with care-giving stressors**

The focus of this section was on how the participants coped with the burden of care-giving. Challenges such as health problems, financial issues, food insecurity, and stigma and discrimination were experienced by caregivers. To deal with care-giving challenges, the participants adopted different coping strategies, which are discussed subsequently.

#### **5.3.1 Coping with health stressors**

According to the findings of this study, almost all the participants reported health problems such as stress and anxiety and high blood pressure. Participants coped with these health challenges by consulting with doctors and receiving free treatment. Due to the Botswana health policy that gives seniors, children, and pregnant women free healthcare services, participants did not need money to consult at the clinic or hospital or buy medication. On the contrary, WHO (2002) found that older adults caring for AIDS

orphans turned to traditional doctors for treatment of different illnesses as they could not afford both the cost of treatment and transportation to the clinics.

Participants with health problems were on prescribed medications, especially for high blood pressure, and Monica, Neo, and Refilwe complemented the medications with Maringa tea. According to the participants, the tea reduced stress and anxiety and Neo confirmed this by noting that *“since I started drinking this tea it has helped a lot in reducing my stress levels.”* Although Lindsey et al. (2003) suggest that older adult caregivers with health problems and little or no money sought treatment from spiritual leaders and traditional doctors instead of visiting the clinic or hospital. On the contrary, the findings of this study indicated that participants went to the hospital and not to the traditional doctors for treatment of different health issues because of the free healthcare services that Botswana provide to older adults and children.

This study also found that participants reduced the stress of care-giving by registering orphaned grandchildren into Daycare Centres as early as three years old to enable them take a break and perform household chores in the absence of the child (ren). This was an indication that these frail caregivers needed respite care programs that would provide them with the opportunity to take a break from childcare. Relatives also helped some participants like Mary to reduce the stress of care-giving by performing household chores such as cooking, taking sick orphans to doctor’s appointments, and picking up or refilling medication for sick orphans and older adult caregivers. Although the unemployed adult children like in the case of Neo were a burden to the caregivers, some of them played a major role in reducing caregivers’ emotional stress and the anxieties they experienced by providing them with financial and moral support.



### **5.3.2 Coping with the financial stressors of care-giving**

Contrary to the above findings, participants in this study dealt with financial challenges by turning to different sources of support such as OAP, BOCP, employment, subsistence farming, and remittances from adult children. Despite these challenges and contrary to the findings of WHO (2002), the participants in this study never withdrew orphans from school because they were aware that once the orphans were registered with BOCP, all their school needs will be provided.

Apart from Refilwe, all the participants faced financial challenges and the severity of these financial stressors differed from one participant to another and depended mainly on the individual's support systems and sources of income. Those participants like Mary, Lesego, Banyana, and Neo who had other sources of financial support (e.g. farming, adult children, and income from rented properties) experienced less poverty than Rose and Mpho who had no support. According to the findings of this study, participants used money from property, farming, employment, OAP, BOCP and support from family members to resolve the financial challenges they faced. In the same vein, previous research argued that households headed by older adults and children cope with financial challenges by borrowing from friends and relatives, using up past savings, selling personal and family assets, such as livestock and renting out property, using wage from grandchildren's labour, old age pension, and relying on community assistance (Naidu & Harris, 2006; UNAIDS, 1999).

As mentioned earlier, the social programs in Botswana helped caregivers coped with the financial stressors of care-giving. For example, four of the participants excluding Rose and Refilwe who were not eligible for OAP, used their OAP to meet the food and

school needs of the orphans and their entire families while waiting for assistance from BOCP. Although participants such as Rose and Mary experienced serious financial challenges after the death of their children, they indicated that the food baskets and the P800 assistance they were receiving from BOCP made a huge difference in their lives. However, when this amount was reduced to P500 in the face of continual increase in the prices of basic commodities, the participants began to experience financial stress. In spite of this development, many of them acknowledged that the financial assistance they got from BOCP lifted them from poverty to a higher and better standard of living.

BOCP was one of the main sources of support for participants and took care of their food and financial needs. In households where the deceased child was unemployed or stopped working long before their death due to illness, their financial and food situation improved once they started receiving BOCP. However, Nyambedha et al. (2003) found that older adult caring for AIDS orphans and vulnerable children coped with financial challenges by withdrawing children from school because of their inability to pay school levies, as education is not free in Kenya and most African countries.

Aside from providing food and financial assistance to the orphans, BOCP also took care of orphans' the school needs and this reduced the stress of care-giving on the older adult caregivers. Those participants who managed the money they got from BOCP well were able to use the money to generate more income by starting small businesses and building low-cost houses that were placed on rent to raise funds. Banyana summarized this by saying,

*When my daughter died I had to put her house on rent to raise money for school transportation for the kids and to feed them as my OAP was not enough and things were difficult. But when the kids started receiving assistance from BOCP, things were better as all their school needs were also taken care of.*

### **5.3.3 Coping with food insecurity and care-giving**

The study found that as a result of the food and financial assistance from BOCP, caregivers such as Rose caring for more than one orphan were receiving more money from the program than their pay cheque when they had full-time jobs. For example, Neo, Lesego, and Mary were each receiving P2000.00 (i.e. P500 per orphan x 4) per month from BOCP, and four food baskets for four orphans in their care. Rose's monthly salary was P1000.00 when she was employed; however, as a caregiver she received P1500.00 per month and three food baskets from BOCP for the three orphans in her care.

Although BOCP and OAP were the main source of food and money for many of the participants, those who had employment, gardens, and farms (subsistence and livestock) used them to augment the assistance from BOCP, especially towards the end of the month when many of participants experienced food shortages. Participants like Monica and Lesego who had unemployed adults in their households and depended mainly on BOCP assistance, tend to buy cheaper food items to ensure that they buy enough for everyone. The above findings were consistent with Sauerborn et al (1996) findings that when faced with the prospects of food shortages, households facing financial challenges may fight back by buying cheap food items and reducing the number of meals per day to meet the consumption needs of their members. In the same vein, UNAIDS (1999) argued that to improve on family food security, when the family breadwinner dies or is terminally ill, family members tend to reduce food consumption and to substitute more expensive food items with cheaper alternatives.

### **5.3.4 Coping with stigma and discrimination**

Although the sample size of this study was small, experiences of stigma and discrimination were limited among the participants. Only one of the eight participants experienced stigma and discrimination from members of the community and her family. Monica avoided stigma and discrimination by keeping the illness of children confidential while Mpho socialized with people who have had similar experiences. Similarly, a study by Steinberg et al, (2002) found that most of the participants dealt with stigma and discrimination by lying about their patient's illness and would say the patient they were caring for was suffering from tuberculosis or pneumonia instead of AIDS. Rose dealt with stigma and discrimination by avoiding people who were likely to discriminate against her and socialized with those who care and were not judgemental.

### **5.4 Conclusion**

This study explored the stressors of and coping strategies adopted by older adult caregivers of AIDS orphans. This goal was achieved through face-to-face in-depth interviews. Based on the findings of this study, participants experienced health and financial issues as well as food shortages and stigmatization. Participants struggled with feeding their families and providing the basic needs of these family members who depended on them especially before they started receiving assistance from BOCP. According to this study, frail caregivers of AIDS orphans like Mary were frustrated because of their inability to take the sick child to and from hospital appointments, perform household chores, and cook for the orphans. This is an indication that although these caregivers had BOCP support and were mentally willing to care for the orphans and

would do anything to support them, some of the caregivers such as Mary, Neo, and Lesego lacked the physical capacity to achieve this goal. Therefore, frail and ill caregivers need childcare as well as food and financial support.

Despite the great work that the government has done and continue to do to improve the situation of the orphans and their caregivers, the government failed to assist orphans gain financial independence and to break the circle of poverty that surrounds them by not created employment skills training programs for orphans who turned 18 and are unemployed. In the absence of these skills training programs, the orphans would find it difficult to survive in highly skilled and competitive job market.

The findings of this study and the literature reviewed revealed that older adult caregivers of AIDS orphans in Botswana faced similar challenges as their counterparts in other African countries but that their coping mechanisms differed. According to Nyambedha et al. (2003) and Kipp et al. (2007) AIDS orphans were taken out of school either because caregivers could not afford school fees or because they had to work and raise money to support their families. On the contrary, this study found that caregivers in Botswana sent orphans to school as early as possible and encouraged them to stay in school in order to take a break from childcare, save money, and to reduce the challenges of household food shortages. Caregivers of AIDS orphans in Botswana adopted the above mentioned strategy to deal with the physical and mental fatigue from care-giving because childcare respite programs and family support are lacking. The availability of social programs such as free education and healthcare, school feeding, OAP, and BOCP helped participants in this study deal with some of the burdens of care-giving. However, caregivers in other African countries lack these social programs and hence, depend on the

unreliable support from relatives and orphans. Therefore, caregivers and orphans in Botswana are better off economically and socially than caregivers in other African countries without social programs.

## **5.5 Recommendations**

The recommendations presented here are based on the literature reviewed and the findings of this study as well as my professional experiences as a social worker and a counsellor in Botswana. To help develop and improve social programs geared towards ameliorating the situation of older adult caregivers and the orphans under their care, the following recommendations were offered.

### **5.5.1 Childcare and caregivers' frailty**

According to the findings of this study, all the participants struggled with childcare, as they did not have the physical abilities required for the daily demands of their young and energetic grand and great grandchildren. Participants like Mary could barely care for themselves, but because they suddenly became the last line of defense or protection for their families, they had to take on the care-giving role despite their frailty. The challenges of childcare faced by caregivers were further complicated if the child was under five years old and HIV positive, as they were frequently sick and needed more attention than the frail caregivers could afford. It was due to these childcare challenges experienced by caregivers that children were sent to school earlier than normal to give the caregivers the chance to rest while the children were in school.

Since sending children to Daycare Centre has proven to be a successful intervention for frail and older caregivers challenged by the burden of childcare, it is therefore, recommended that the government of Botswana should seriously look into the possibility of childcare respite programs and this could mean expanding and making the services of Daycare Centres available to all older adult caregivers with younger children who need help.

### **5.5.2 Counselling and care-giving burden**

Eight caregivers participated in this study, and only one of them reported receiving counselling despite the stress and trauma experienced by all of them due to the death of their adult children and the challenges of care-giving. These caregivers lost their adult children to AIDS before becoming surrogate parents with limited physical and mental capacities and resources.

In the Tswana culture as in most African traditions, youth are responsible for the care of children and their old and frail parents but because of HIV/AIDS and other socio-economic factors, this status-quo is changing and older adults are becoming caregivers. These changes are taking place so fast that most or all of these caregivers needed counselling to help them deal with the trauma, stressed, and anxiety brought about by the death of their children and the responsibilities that came with it. According to the findings of this study, a majority of the participants were still grieving the death of their children as most of them became emotional and tearful during the interviews. Therefore, BOCP should incorporate counselling services and exercise programs into its program to help caregivers go through grief and deal with the stress of care-giving.

### **5.5.3 Orphans turning 18 and food shortages**

Based on my personal and professional experiences, a child in the Tswana and many Africa cultures does not become an adult just because of their age alone but because they also have the resources and capacity to manage their personal affairs. However, according to government policies in Botswana, when children turn 18 years old, they are automatically considered adults, are expected to be independent, and to fend for themselves. This was the yard stick used by BOCP to kick orphans who turned 18 out of assistance and thereby shifting the responsibility to care for them to their frail grandparents to provide for their daily needs especially if they are unemployed. Therefore, orphans who were still in school or have completed school but were unemployed depended on their siblings' food baskets and this created constant food and financial shortages in their households. Given these challenges, it is recommended that BOCP should consider allowing orphans who turn 18 and were unemployed or still in school to receive assistance until when they complete school or get a job. It is also recommended that BOCP should design and implement skills development training programs that would enable unemployed orphans to acquire the necessary skills to compete in the job market.

### **5.6 Suggestions for further research**

Given that the sample size for this study was small and could not be generalised, a comprehensive and in-depth national study on the stressors and coping strategies of older adult caring for AIDS orphans and vulnerable children in Botswana is required to provide additional insight into the general situation of the caregivers and the children under their



care. Furthermore, as older adult male caregivers were not included in this study, an in-depth nation-wide study of all caregivers should focus on both male and female caregivers in the country with a particular interest on the difference between care-giving provided by men and women.

Finally, orphans who are cared for by their fail and sick grandparents do play a very significant role in caring for themselves and their grandparents. However, this study did not focus on the orphans and other stakeholders who also contributed in the care-giving process. Therefore, further research could give inside into the role and contributions of the orphans and other stakeholders in the care-giving process.

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# APPENDICES

## Appendix A

### Guiding interview questions

#### 1. Socio-Demographic Information

1. Name of participant .....
2. Number (pseudonym) assigned to participant: .....
3. Gender of participant:            1. Male                             2. Female
4. Age of participant (may use Omang i.e. ID if possible to confirm): .....
5. Marital status of participant: 1. Married     2. Widowed    3. Separated     4.  
Never married             5. Cohabiting     6. Other  
specify.....
6. Highest education completed by caregiver 1. Never gone to school             2.  
Primary     3. Secondary     4. Professional Training college     5. University   
6. Other specify.....
7. How many people live in your household? .....
- Number of orphans: .....
8. What are the ages of the orphans and other children you live with?  
Age of orphan 1: ..... Orphan 2: ..... Orphan 3: ..... Ages of other kids  
specify: .....
9. If some of the children are not in school, why not? 1. Too young  2. Sick   
3. No money  4. Care of sibling/the sick  5. Help in chores/farm   
6. Other specify.....
- 10 If you live with adults, what are their  
Ages? .....
- Professions: .....
11. How long have you cared for orphans? .....
12. How many relatives have you lost to HIV/AIDS related illnesses in the past five  
years? .....

13. How are you related to the deceased? 1. Son  2. Daughter  3. Brother  4. Sister  5. Other specify.....

14. What was/were their ages and gender? ..... Age: .....

15. How were they supporting the family before their death? .....

16. A description of the participants':

a. Homes (e.g. type of house, amenities available eg water/electricity, etc)

.....  
.....

b. Daily activities

.....  
.....

17. Interviewer's thoughts and impressions at the end of the session:

.....  
.....

## **2. Stressors of care-giving and coping strategies**

### **A. Stressors of care-giving**

Please tell me how child care and rearing has affected you in the following areas:

a. Personal health

b. Your financial situation e.g. source of income, paying tuition, kids' health care, etc

c. Food security in your household

d. Stigma and discrimination

### **B. Coping strategies**

Please describe in detail how you have been able to deal with the stressors of care-giving with regard to the following:

a. Personal health issues

b. Financial problems

c. Shortage of food in household

- d. Stigma and discrimination
- e. Aside from the above coping strategies, how else do you deal with these challenges? Please explain.

**C. Suggestions from participants**

What do you think could be done to help you deal with the challenges of care-giving in a more effective way?

- a. Personal health issues
- b. Specifically what could the government do to assist you?
- c. How can non-governmental organizations help?
- d. Are there other organizations or resources that you think may improve your situation? Please explain.

D. Are there other insights and suggestion you would like to offer regarding the challenges and coping strategies of care-giving?

Thank you for taking part in this interview.

## Appendix B

### Participant consent form

**Project Title:** Stressors and coping strategies of older adults as caregivers in the era of HIV/AIDS: A case study of Botswana

**Researcher:** Irene Anabenu Forcheh  
Faculty of Graduate Studies and Research  
University of Regina  
Phone: (306) 999-0841  
Email: [anabenuf@gmail.com](mailto:anabenuf@gmail.com)

**Supervisor:** Dr. Abu Bockarie  
**Department:** Adult Education and Human Resource Development  
Phone: (306) 585-5601  
Email: [Abu.bockarie@uregina.ca](mailto:Abu.bockarie@uregina.ca)

**Research Assistant:** A research assistant will be recruited to assist with data collection, analysis, and providing therapy to participants when needed.

**Purpose of the Research:**

The purpose of this study is to explore the stressors and coping strategies of older adult caregivers of HIV/AIDS orphans in Botswana

**Procedures:**

1. Each participant will participate in a face-to-face in-depth interview in his or her home or at any location of his or her choice. The interview will last for about 45 minutes and with participants' permission, the interviews will be digitally recorded and transcribed.
2. The researcher and her assistant will ask participants questions about the care-giving stressors they face, the strategies they use to cope with those stressors, as well as some suggestions about how their care-giving roles and responsibilities could be improved.
3. Participants will be advised about the procedures and goals of the study as well as their role in data collection.

**Funded by:** N/A

**Potential Risks:**

4. There are no known or anticipated risks to participants. However, Lifeline Botswana (an NGO that provide free counselling to people with emotional, social, and behavioural problems) will also be

contacted by the researcher so they could provide counselling to participants if necessary.

**Compensation:** N/A

**Confidentiality:**

5. The identities of all participants concealed by replacing their names with pseudonyms. Any personal descriptors of participants will be removed prior to the preparation of the thesis. All copies of transcripts of the interview data will be stored securely by the researcher. Audio tapes and transcripts will be stored separately. No other person other than the researcher and her assistant will know who participated in the study.
6. While all efforts will be made to protect the confidentiality of participants' data, their complete anonymity cannot be guaranteed due to the small sample size and the recruitment process.

**Storage of Data:**

- Paper records, which include informed consent forms and transcripts, will be stored in a locked filing cabinet. Electronic data, including audio recordings and transcripts will be stored in the researcher's laptop, which is password protected. The audio tape and paper records will be stored in a locked filing cabinet where only the researcher has access to them
- All data will be stored for three years after the study
- After three years, all paper records will be shredded and electronic files will be deleted

**Right to Withdraw:**

Your participation is voluntary and you may answer only those questions that you are comfortable with. You may also withdraw from the study for any reason and at any time without an explanation or penalty of any sort.

Your right to withdraw from the study will apply until the end of data collection. After that, it is possible that some form of research analysis and interpretation would have taken place. Therefore, it may not be possible to withdraw any data at this stage.

**Follow up:**

- a. To obtain results from the study, please contact the researcher using the information at the top of this page.

**Questions or Concerns:**

- b. Contact the researcher using the information at the top of this page if you have any questions and concerns

- c. This project has been approved on ethical grounds by the University of Regina Research Ethics Board and the Research and Development Ethics Committee at Ministry of Local Government, Gaborone, Botswana. Any questions regarding your rights as a participant may be addressed to the Research and Development Ethics Committee at (267) 3658-400 or to the University of Regina Research Ethics Board at (306) 585-4775 or research.ethics@uregina.ca.

**Consent:**

Your signature below indicates that you have read and understand the information provided in the consent form; that you have had an opportunity to ask questions about the study and your questions have been answered to your complete satisfaction. You consent to participate in the research project. Verbal consent means the participant may not sign the consent form but it should be indicated as such below.

Researcher: Irene A. Forcheh

Signature: Irene Forcheh Date: 2012-02-28

Name of participant:

Signature:

Date:

If verbal consent given, please indicate:

A copy of this consent will be left with you, and the researcher will keep a copy.

## Appendix C

### Invitation letter to participants

Irene Forcheh  
Faculty of Graduate Studies and Research  
University of Regina  
Regina, SK  
S4S OA2

February 18, 2012

Dear Sir/Madam,

**Re:** Stressors and coping strategies of older adults as caregivers in the era of HIV/AIDS: A case study of Botswana

My name is Irene Forcheh, and I am a graduate student in the Faculty of Graduate Studies and Research at the University of Regina. I am writing to request your assistance.

As part of the requirements for the Master degree in Gerontology, I am conducting a study entitled: “*Stressors and coping strategies of older adults as caregiver in the era of HIV/AIDS: A case study of Botswana*”. The purpose of the study is to explore the challenges face by older adult caregivers of AIDS orphans and their coping mechanisms.

The Research Ethics Board at the University of Regina and the Research and Development Ethics Committee at Ministry of Local Government, Botswana have approved this study. If you have any questions or concerns about your rights or treatment as a participant in this study, you may contact the Chair of the Research Ethics Board at (306) 585-4775 or by e-mail at [research.ethics@uregina.ca](mailto:research.ethics@uregina.ca) or the Research and Development Ethics Committee at Ministry of Local Government at (267) 3658-400

The proposed study is significant because it may stimulate a comprehensive discussion of the challenges of older adult caregivers, and contribute to the knowledge-base about the dynamics of care-giving in contemporary Botswana. In addition, the findings of the study may assist the relevant authorities in formulating and implementing appropriate interventions, such as stress management and social welfare programs that will facilitate the work of older adult caregivers. Further, it is likely that this study will contribute to the knowledge base on the stressors and coping strategies that older adult caregivers adopt to care for AIDS orphans. Finally, the study may lead to further research on the stressors and coping strategies of older adult caregivers in Botswana.

As part of this study, I will be conducting interviews with older adults who have cared for, or are currently caring for AIDS orphans.

I write to invite you to participate in a 20-45minutes unrecorded interview and a 45 minutes tape-recorded interview for this study. Shortly after ethics approval of the study, my research assistant or I will contact you to confirm your willingness to participate in the study, answer any questions you might have, and discuss with you your preferred date, time, and location of the interview.

You have my personal assurance the information you provide will be treated in the strictest confidence. All data will be coded through the use of pseudonyms, and audiotapes, transcripts and disks will be stored separately. Any personal descriptors of you will be removed prior to the preparation of my thesis. No identifying information about you will be included in direct quotes, to ensure confidentiality. The data will remain in my database, and any records on computer disk will be kept in a secure folder requiring a password for access. All documentation about the study will be destroyed three years after the successful completion of my thesis.

If you agree to participate in an interview for this study, you will be required to complete the consent form attached before the interview. Remember to keep a copy of the signed consent form for your records.

Please note that this interview is a voluntary contribution of your time and thoughts and you may withdraw your participation from the study at any time without consequences.

If you have any questions about this study, please feel free to contact me at (306) 205 9129/999 0841 or e-mail at [anabenuf@gmail.com](mailto:anabenuf@gmail.com)

I hope you will find time to participate in the interviews.

Sincerely,

Irene.



# Appendix D

## Research ethics approvals



OFFICE OF RESEARCH SERVICES  
MEMORANDUM

DATE: May 31, 2011

TO: Irene Anabenu Forcheh  
Faculty of Education

FROM: Dr. Bruce Plouffe  
Chair, Research Ethics Board

Re: **Stressors and Coping Strategies of Older Adults as Caregivers in the Era of HIV/AIDS: A Case Study of Botswana (File #93S1011)**

Please be advised that the University of Regina Research Ethics Board has reviewed your proposal and found it to be:

- 1. APPROVED AS SUBMITTED. Only applicants with this designation have ethical approval to proceed with their research as described in their applications. For research lasting more than one year (Section 1F), **ETHICAL APPROVAL MUST BE RENEWED BY SUBMITTING A BRIEF STATUS REPORT EVERY TWELVE MONTHS**. Approval will be revoked unless a satisfactory status report is received. Any substantive changes in methodology or instrumentation must also be approved prior to their implementation.
- 2. ACCEPTABLE SUBJECT TO MINOR CHANGES AND PRECAUTIONS (SEE ATTACHED). Changes must be submitted to the REB and approved prior to beginning research. Please submit a supplementary memo addressing the concerns to the Chair of the REB.\*\* Do not submit a new application. Once changes are deemed acceptable, ethical approval will be granted.
- 3. ACCEPTABLE SUBJECT TO CHANGES AND PRECAUTIONS (SEE ATTACHED). Changes must be submitted to the REB and approved prior to beginning research. Please submit a supplementary memo addressing the concerns to the Chair of the REB.\*\* Do not submit a new application. Once changes are deemed acceptable, ethical approval will be granted.
- 4. UNACCEPTABLE AS SUBMITTED. The proposal requires substantial additions or redesign. Please contact the Chair of the REB for advice on how the project proposal might be revised.

  
Dr. Bruce Plouffe

cc: Dr. Abu Bockarie – Faculty of Education

\*\* supplementary memo should be forwarded to the Chair of the Research Ethics Board at the Office of Research Services (Research and Innovation Centre, Room 109) or by e-mail to [research.ethics@uregina.ca](mailto:research.ethics@uregina.ca)

Phone: (306) 585-4775  
Fax: (306) 585-4893  
[www.uregina.ca/research](http://www.uregina.ca/research)



REPUBLIC OF BOTSWANA

Block 8, Government Enclave, Khama Crescent  
Private Bag 002, Gaborone, Botswana  
Tel: (+267) 361 1100 E-mail: mlha-pro@gov.bw  
Fax: (+267) 390 7426 Website: www.mlha.gov.bw



**REF: CHA 1/17/2 XIX (47)**

**21 July 2011**

Ms Irene Forcheh  
University of Regina  
Regina, Saskatchewan  
Canada

Dear Madam

**GRANT OF A RESEARCH PERMIT**

Your application on the above matter refers.

You are hereby granted permission to carry out research titled "**STRESSORS AND COPING STRATEGIES OF OLDER ADULTS AS CAREGIVERS IN THE ERA OF HIV/AIDS IN BOTSWANA**". Permission is granted subject to the following conditions:

1. Copies of any report/video produced are deposited with the Director of Research and Development office of University of Botswana, Botswana National Library Service, Botswana National Archives and Records Services, and Ministry of Labour and Home Affairs.
2. The Permit does give authority to enter any premises, private establishment or protected area. Permission for such entry should be negotiated with those concerned.
3. The permit is valid for a period beginning **25 July 2011 to 09 September 2011.**
4. You shall conduct the study according to the particulars furnished in the application form.
5. Failure to comply with any of the above - stipulated conditions will result in the immediate cancellation of the permit.

You are also requested to submit a copy of the report to the Ministry of Labour and Home Affairs.

Thank you.

Yours faithfully



S. Sithole  
for/**PERMANENT SECRETARY**