A Study of the Life Condition of Older Caregivers to their Grandchildren Orphaned due to HIV/AIDS in Kolfe Keraniyo Sub-City, Addis Ababa

BY:

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Abstract

This study assesses the living conditions of older care givers to children orphaned due to HIV/AIDS in selected Woredas of Kolfe-Keraniyo Sub-City, Addis Ababa. The study employed qualitative method. In-depth interviews and focus group discussion were used as techniques of data collection. A total of 16 older care givers aged 60 and above were participants of the study. In addition, 2 representatives from MoLSA and Tesfa Social and Development Organization were participated in the study. The participants were selected using purposive sampling. The ABC-X model of family stress theory was used as a conceptual framework to guide the study. The findings of the study indicated that the high prevalence of HIV/AIDS among the younger generation in the study area and the resulting death places a huge psychological, social and economic burden on the elderly people who are caring for children orphaned due to the disease. Loss of income and resources, ill physical and health condition, stigma and discrimination and psychological distress were some of the difficulties faced by elderly people in caring for their grandchildren. This study found that elderly caregivers are using various strategies in order to cope up with the difficulties they face, though they are not providing them much help. Due to the fact that the challenges faced by older caregivers are multidimensional and complex, it is suggested that a combination of intervention strategies and approaches should be taken to reduce the vulnerability of older care givers and their families. In this regard, the researcher suggests a number of relevant areas of social work practice to address problems of the elderly care givers. Accordingly, policy responses; advocacy and awareness raising to maintain the traditional support networks, and designing and implementing participatory older people focused relevant social work interventions at micro, mezzo and macro levels are recommended.

Keywords: Older caregivers, coping, AIDS orphans, HIV and AIDS
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List of Abbreviations

AIDS: Acquired Immunodeficiency Syndrome

OVC: orphaned and vulnerable children

CBO: community based organization

CSA: Central statistical Agency of Ethiopia

FDRE: Federal Democratic Republic of Ethiopia

FGD: Focus group discussion

FHAPCO: Federal HIV/AIDS Prevention and Control Office

HIV: Human Immunodeficiency Viru

MoLSA: Ministry of Labor and Social Affairs

TSDA: Tesfa Social and Development Association

NGO: Non-Governmental Organization:

UNICEF: United Nations Children’s Fund

UNAIDS: Joint United Nations Programme on HIV/AIDS

WHO: World Health Organization
Chapter One

Introduction

1.1. Background

It is believed that due to the impact of AIDS epidemic, especially poor countries will continue to face an increasing number of AIDS induced deaths and the resulting orphanhood. HIV/AIDS has large social, psychological, economic and demographic impacts on both individuals, families, communities and society, thus leading to painful stress, disability, death of adult parents and children, and the resulting orphanhood. Because people in their most productive years (15-49 years old) are most commonly infected with HIV/AIDS, the disease threatens broader development progress in many low-income countries, especially those found in sub-Saharan Africa(UNAIDS & UNICEF,2004). In 2013, UNAIDS reported that 14.8 million children in that region have already lost one or more parents to the disease, and economic growth is held back as a result.

Ethiopia is among those countries most affected by HIV and AIDS. The existence of HIV infection in Ethiopia was recognized in early 1980s with the first two reported AIDS cases in 1986. Since then, the epidemic has rapidly spread throughout the country. The epidemic peaked in mid-1990s and started to decline in major urban areas since 2000 while stabilizing in rural settings. The national adult HIV prevalence in 2008 was 2.2% with an estimated 1,037,267 people living with HIV/AIDS. Out of the estimated 5.4 million orphans, 886,820 were orphaned due to AIDS. There were an estimated 58,000 deaths due to AIDS in 2008. The estimated national adult HIV incidence of 0.28% in 2008 translates to over 125,000 new HIV infections on
top of over 1 million Ethiopians living with HIV. With the current status it is evident that HIV and AIDS remain formidable development challenges to the country (FHACO & MOH, 2009).

HIV/AIDS impacts those infected by the virus, their families, and their communities; this is especially true in developing countries. Families in developing regions of the world are normally left with, not only the burden of caring for the sick for a long period of time, but also the expenses incurred during the sickness and death of loved ones infected with HIV/AIDS. This is an acute strain especially on households with extremely scarce resources in developing countries. In most cases, prime-aged adults are the ones dying, and their older (or younger) kin are the ones left with multiple burdens. These kin must give care to sick individuals and to orphaned children, and cover expenses incurred from the sickness and funeral (HelpAge International, 2003).

As young and middle-aged kin infected with the HIV virus give way to AIDS related diseases, family structures are being affected. Older family members have had to assume care responsibilities for affected young children. Indeed, numerous older persons are now central to the survival of the increasing number of orphaned and vulnerable children as well as the care for sick adult children. Many older people have become care givers; they have become responsible for providing economic, social and psychological care and support to orphaned and vulnerable children (HelpAge International, 2007).

The care responsibilities of these older people must assume enormous burden on them. Often they presume these responsibilities without adequate knowledge, resources or support. They commonly suffer physical, health and emotional effects from the strain of care giving. The
roles they play and the contributions they make through care giving are typically unrecognized and/or unsupported. They are often unable to meet their own health care needs- let alone those of the people for whom they are caring (May, 2003).

The African extended family has traditionally nursed its sick and absorbed its orphans without legal process (Alpaslan & Mabuthu 2005, p: 276). Many governments and major international donors have therefore reacted to growing evidence of the impact of HIV and AIDS on households by suggesting that ‘traditional’ coping mechanisms would minimize the impact and allow households and communities to absorb the loss of members (Economic Commission for Africa, 2009). However, this is yet to be demonstrated, since there is growing evidence of multiple crises faced by those families now being headed by the elderly in Africa (Makiwane, Schneider & Gopane, 2004).

Although Ethiopia is a country with young population of 46 per cent under the age of 14, over five per cent of the 81 million Ethiopians are aged 60 years or more. This proportion of older persons is anticipated to nearly double to nine per cent by 2050. Older men who live to 60 are expected to live additional 15 years and older women additional 16 years after their 60th birthday (CSA, 2007). The rapid growth of population ageing in Ethiopia and the impact of HIV and AIDS add another dimension to the role of older persons. HIV and AIDS affects older people in two main ways: the elderly are themselves infected with HIV, making them vulnerable to many health and socio-economic challenges, and it places a burden on them as careers since many have to care for their sick children and are often left to look after orphaned grandchildren who are also infected .The extended family used to be relied upon to provide subsistence and care for older persons (MoLSA, 2006).
This study was conducted in selected Woredas of Kolfe area including Woreda 10, 11 and 12 of Kolfe Keranioyo Sub-city, one of the areas in Addis Ababa where the prevalence of HIV/AIDS is very high, according to Addis Ababa HAPCO. Since the beginning of the 1990s, the sickness that spread at an alarming rate has been pneumonia, which is closely linked to HIV/AIDS. According to the Kolfe Keranio Health Centre, most of the people in the locality who are said to have died of pneumonia are believed to be victims of HIV/AIDS, which is attacking the generation aged 20-45. According to the Health Centre, among a total of 1,423 individuals, (491 male and 932 female) who have tested for HIV/AIDS in 2004, 20.1% of the females and 9.3% of the males were found to be HIV positive, most of who were young people.

According to the Kolfe keranioyo Sub-City Labour and Social Affairs office the effects of HIV/AIDS pandemic in the community are complex for the following reasons.

- It has increased the number of orphaned children in the community. As a result, much of the aid provided by NGOs that could have been invested in development activities is diverted to orphans.

- The responsibility of giving care to children has devolved to grandparents, extended family members and the eldest child. Grandparents have also lost their supporters and have become more vulnerable to economic problems.

- The community has lost productive citizens such as nurses, government employees and some of those who served local iddir with an impact on the development of the community.
The number of orphans has been increasing in the last ten years because their parents die due to HIV/AIDS. According to the Tesfa Development Association reports of 2012/13, about 871 orphans registered for help. These include 341 (208 female) full orphans, 387 (249 female) who lost their fathers and 112 (58 female) who lost their mothers. Generally, close relatives, often grandmothers, are shouldering responsibility for bringing up these children. Hence, the aim of this thesis is to assess the situation of older care givers to their grandchildren orphaned as a result of HIV/AIDS by specifically focusing on older care givers in Woredas 11, 12 and 13 of Kolfe Keraniyo Sub-City in Addis Ababa.

1.2. Statement of the Problem

Older people in most developing societies are a vulnerable group as a result of a lifetime of hardship, malnutrition, poverty and, in older age, high susceptibility to chronic diseases. The AIDS pandemic is now posing an additional burden on them. In their old age, when they may require support and expect to be looked after, they have to take on the role of caring for others, in most cases without even the basic necessary resources. Lacks of economic, social and psychological support constantly restrict their ability to provide the care expected of them (HelpAge International, 2007).

HIV/AIDS in Ethiopia affects older people directly as well as indirectly. It has exposed older people to various economic and emotional problems such as poverty and loneliness, through the loss of their children at a time when they were expecting to be cared for and
supported by them. In spite of what older people offer by caring for the sick and looking after orphaned grandchildren, their level of awareness about the virus is very low (MoLSA, 2006).

The experiences of NGOs in Ethiopia also indicated that older people often take additional responsibility of caring for HIV/AIDS orphans when they lose their sick adult children. They are often left with no means of survival to bring up these children. These NGOs also observed a lot of trauma among older caregivers due to the sudden burden they have to carry, a role they are taking on when they have lost their physical strength and are themselves suffering from poor health and extreme poverty. The welfare of their grandchildren when they die is a constant source of worry (HelpAge International, 2009).

There are few studies (Meseret, 2012; Mussie, 2006; Yohannes, 2006; Zena, 2006; Philipos, 2002) conducted in Ethiopian that investigate the experiences of caregivers looking after children orphaned by AIDS. However, these studies, which the researcher who has carried out this research is aware of, tend to focus on the care provided to children orphaned due to HIV/AIDS epidemic by different groups such as by extended family, volunteer groups, institutions and nongovernmental organizations without specifically and adequately addressing the care provided by older people (grandparents) to AIDS orphaned children and the life condition of these older caregivers. Thus, there is a need for commissioning this study to fill this gap and this study specifically assesses the living condition of older caregivers to their grandchildren orphaned due to HIV/AIDS epidemic. Based on the gap identified, this study brings the following research questions.
1.3. Research Questions

**Major Research Question**

What are the experiences of elderly as care givers to their grand children orphaned due to HIV/AIDS in the study area?

**Specific Research Questions**

1. What are the responsibilities of older care givers as care providers to AIDS orphaned grand children in the study area?
2. What are some of the challenges care givers face in providing care to AIDS orphaned children in the study area?
3. What are the coping strategies used by elderly caregivers to overcome these challenges in the study area?

1.3. Objective of the Study

**General Objective**

To assess the life condition of older people who provide care to their grand children orphaned as a result of HIV/AIDS in Woredas 11, 12 and 13 of Kolfe Keraniyo Sub-City in Addis Ababa.

**Specific Objectives**

- To identify the responsibilities of older care givers as care providers to AIDS orphaned grandchildren.
- To find out the challenges experienced by older care givers in the process of providing care to AIDS orphaned grandchildren.
To examine the coping strategies used by older caregivers to overcome the challenges they face in care giving process.

To find out the available resources and support systems for elderly caregivers in the study area that help them to support orphan children.

1.4. Operational Definition

*Older People:* refers to persons who are 60 years of old and over.

*Older Care giver:* a member of a household, extended family who is 60 years and above and who is giving social, economic, and/or psychological care and support and/or personal care and assistance to children orphaned due to AIDS.

*Orphan:* Children who lost either one or both of their parents due to HIV/AIDS.

*Coping:* strategies/mechanisms used by elderly in order to deal with the challenges they face in providing care to their grand children orphaned due to HIV/AIDS.

1.5. Significance of the Study

HIV/AIDS and its devastating impacts such as premature deaths, orphan-hood, lack of caregivers to the elderly, etc., are so complex and present serious development challenges. Thus, this study seeks to develop greater understanding on theses and the study helps to map out some social work interventions, which would help ameliorate the challenges faced by older care givers to children orphaned due to HIV/AIDS epidemic.
Different researchers have tried to assess the situation of HIV/AIDS in Ethiopia, but its impact on older people has not been adequately assessed. As this study focuses on assessing the living condition of the older caregivers to children orphaned due to HIV/AIDS epidemic, the findings of this study may provide some information for those who are interested to conduct further investigation on the issue under discussion.

In countries like Ethiopia, where there is insufficient information available on the multidimensional impacts of HIV/AIDS, this study may give an insight on the major problems facing older persons due to the epidemic. Moreover, the suggestions forwarded on the existing policy issues and practices based on the findings of the study may indicate relevant social work interventions to government organizations, NGOs, religious institutions, community-based organizations and associations working with older people.
Chapter Two

Literature Review

This chapter presents a review of literatures relevant to the study. It draws on the literature from studies across the globe, particularly in developing countries where HIV/AIDS prevalence is high. Hence, this chapter covers sub-topics such as impact of HIV/AIDS on older people; roles of older people as care providers to children orphaned due to HIV/AIDS; coping strategies employed by older care givers to deal with the challenges they face in the caring process and available resources and support systems to help older care givers to minimize their problems they face as care providers to AIDS orphaned children. This chapter also highlights the state of older people in Ethiopia and measures that have been taken by different actors to enhance the welfare of older people in the country.

2.1. Impact of HIV and AIDS on Older People

Social Impact

Studies show that HIV and AIDS attack mostly the reproductive and economically active section of the population, changing family composition by decimating the young adult population and creating elderly-headed and child-headed families ((Makiwane; Schneider & Gopane, 2004; AVERT, 2009; Drimie, 2002; Schatz & Ogunmefun, 2007; Alpaslan & Mabutho, 2005:p.276). The traditional support system for the elderly is hereby destabilized (Schatz, 2007; Mussie, 2006).

In sub-Saharan Africa alone millions of children grow up without parents and often live with grandparents (UNAIDS & UNICEF, 2004). A review of the composition of households
consisting of older adults in 24 countries of sub-Saharan Africa showed that 59% live with children and 46% with a grandchild, and that older adults are more likely to be living with double orphans (where both parent have died) in countries with high AIDS-related mortality (Zimmer & Dayton 2005: p.297). Reviews show that elderly-headed families cannot cope with the increasing number of orphans created by the disease (AVERT, 2009). Social networks are reported to have collapsed due to the pressure of having to support orphaned children (Halkett, 2000 in Aliber, 2001). Intra-familial relations become strained if conflict over custody arises or grandparents judge other family members to be negligent of the grandchildren (Alspaslan & Mabutho 2005:p.277). The roles of the elderly are seen to be changing to being care-givers of their adult children stricken with HIV and AIDS, guardians of their orphaned grandchildren, and surrogate parents for these grandchildren (HelpAge International, 2007), which results in an increased burden of caring resting on the elderly.

Increased social responsibility of the elderly is reported, due to prolonged travelling and absence from their homes to care for sick and orphaned grandchildren (Ssenengozi 2009; Schatz 2007:p.151). This increase results in social isolation, because the elderly cannot afford the time or money to take part in social activities (HelpAge International, 2008). Another reason for reducing participation in social activities is fear of stigmatization, as reported by Alpaslan and Mabutho (2005:p. 277).

**Economic Impact**

A scarcity of resources is a serious issue for caregivers. A significant number of studies related to the financial aspect of grandparent-as-parents have highlighted that they live below the poverty line (Smith; Hamon; Ingoldsby & Miller, 2000). According to Backhouse (2006) lacking
enough resources to provide for the needs of the household may generate another health problem such as anxiety and stress. As a result the household head is more likely to worry in excess and feel guilty for not being able to meet the minimum needs of all “dependents”.

The literature reveals that many persons affected by HIV and AIDS in sub-Saharan Africa remain at home, with the main burden of their care resting almost entirely on family members, who in most cases are elderly females (Ogunmefun & Schatz, 2009). The literature also shows that whilst the economic consequences for the elderly who give care to the sick and orphans or have lost children to HIV and AIDS cannot be quantified, their impact is great.

The care-giving role of the elderly is such that it overwhelms their livelihood, forcing them to contend with various demands in terms of coping with increased health care costs, including debts incurred as a result of HIV and AIDS-related illnesses (HelpAge International 2003) and meeting the transport and medical costs of ailing children (May, 2003; Ssengonzi 2007:p.349), paying school fees for orphaned grandchildren (HelpAge International, 2003), and paying the funeral expenses of their family members (Schatz & Ogunmefun, 2007:1392; Bock & Johnson, 2008). They also have to meet the costs of grandchildren (some of whom may be HIV positive) for whom they must now provide care (HelpAge International 2003; Ssengonzi 2007:p.249; Okayo, 2004).

Extended family members are not in a position to assist elderly care-givers (Alpaslan & Mabutho 2007:p.277) due to harsh economic conditions. Worst of all, the grandmothers are left without any inheritance from the deceased parents of AIDS orphans (Alpaslan & Mabutho
The elderly are seen as being financially abused (Makiwane; Schneider & Gopane, 2004:p.12).

The literature shows that the economic impact of HIV and AIDS on the elderly is overwhelming to them, and they seem to have no financial support. The least economically productive in society – the elderly – bear the financial burden of caring for the sick relatives and orphaned grandchildren left behind. As a result, food insecurity is found to be prevalent in elderly households, and the care-giving responsibilities exacerbate the already compromised nutritional status of the elderly (Charlton & Rose, 2001).

**Psychological Impact**

The literature review on HIV and AIDS revealed various psychological impacts on the elderly. For those that are infected, experiences of hopelessness and loneliness, shame and fear of being infected are documented (Landman, 2008: p.57). Because of the myth that the elderly are asexual, infected elderly women feel humiliated by their sexuality and their own fear bars them from seeking health care and support since they fear stigmatization (Otani 2004; Mlobeli, 2007).

Reports on caring activities show that the elderly worry about the impending death of adult children as well as the emotional stress of nursing terminally ill relatives and being infected during the process of caring (Alpaslan & Mabutho 2005, p.277; HelpAge International 2003; Ssengonzi 2007:p.342). When the children eventually die, grandparents endure the trauma of the loss of family members and have to cope with the stigma associated with HIV and AIDS (HelpAge International, 2003), even long after the death of their children. Caring for
grandchildren is also burdensome, since orphans often refuse to accept the authority of the older persons and the elderly experience problems in disciplining them (Alpaslan & Mabutho 2005:p.277).

In certain instances the elderly reduce participation in social activities, since they fear negative community reactions towards the HIV-positive grandchildren in their foster care. This is compounded by concerns over grieving children who must also cope with the community stigma attached to and often irrational fear surrounding AIDS (Alpaslan & Mabutho 2005, p. 277).

In summary, HIV and AIDS have a negative economic, social and psychological impact on the well-being of the elderly who are either infected or affected by this pandemic. This negative impact manifests in many forms, including financial burden of caring for the sick relatives and orphaned grandchildren, destabilized social support system for older people fear, trauma and grieving, isolation, hopelessness and stigmatization.

2.2. Responsibilities of Older People as Care Givers to Orphan Children

The majority of elderly citizens in Sub-Saharan Africa endure the pain of seeing their children suffering from HIV/AIDS. They often have to bury their own children. After the burial, elderly citizens have to assume the role of being parents again. Emotional strain may result from negative community reactions toward caring for their grandchildren or concerns about the costs of childcare, and physical strain and exhaustion can result from additional work required to cover these costs (Knodel; Zimmer; Kim & Puch, 2003).
A study conducted by Nyambedha, Wandibba & Aagaard-Hansen in Kenya indicates that elderly people who care for AIDS orphans are faced with enormous difficulties. Elderly caretakers face major difficulties in caring for the orphans in terms of schooling, food and medical care. Many older persons are suddenly faced with a situation where they have to resume a parental role and all the responsibilities that go with it, while having no reliable source of livelihood, and in many cases they do not have the physical capability to undertake such responsibilities (Nyambedha, Wandibba & Aagaard-Hansen, 2003).

Another study that was carried out by May in Zimbabwe found that the majority of caregivers for AIDS orphans were grandmothers. This reveals that the elderly play a great role in taking care of grandchildren when their parents die. They support terminally ill adult children and their orphaned offspring in poverty, without recognition, and often in poor health (May, 2003).

2.3. Available Resources and Support Systems for Older Caregivers

A study carried out in Kenya finds that the elderly may employ various forms of support. Older grandchildren, especially boys, might be forced to withdraw from school and look for jobs in order to support the household. Nyambedha, Wandibaa & Aagaard-Hansen (2003) state that elderly worked for wealthier members of the community, they often worked long hours for little pay. In some cases children become the subject of exploitation. Nyambedha, Wandibaa & Aagaard-Hansen (2003) further state that orphans also engage in a range of activities such as charcoal burning, fishing, mining and sometimes cutting wood to sell as firewood in order to earn an income.
Another study carried out in South Africa on the elderly as HIV/AIDS as caregivers used focus groups as the data collection method. The respondents were men and women aged 60 and above who were caring for both sick adult children and AIDS orphans in their households. In elderly headed households pension grants are an important source of support. Social grants, especially pensions, have been reported as the main source of income in many studies. This study also found that neighbours and relatives, particularly extended families, are a good source of support and this includes community organizations such as non-governmental organizations. A small number of elderly caregivers reported being involved in income generating activities such as raising chickens, gardening, sewing, or selling drinks to supplement the family income (Nyambedha, Wandibaa & Aagaard-Hansen, 2003). Nyambedha, Wandibaa & Aagaard-Hansen (2003: p. 43) found that “respondents also report providing psychological and emotional support to each other by talking about their problems and that appears to provide the elderly with the opportunity to identify with and relate similar experiences, although there are concerns about confidentiality”.

The church was also identified as a source of support, especially for offering prayers during times of hardship. All of the caregivers interviewed were church members and frequently acknowledged their belief and trust in God to improve their situation, and they also encouraged the children in their care to pray (Nyambedha, Wandibaa & Aagaard-Hansen, 2003). Other studies claim that the elderly may rely on extended families or relatives for support. Social networks help reduce the potential financial burden on the elderly (Weinreb, 2002).

Government and societal responses to the needs of older caregivers have been desperately inadequate despite the fact that the writing has been on the wall for so many years (Karim &
Karim, 2005). Matshalaga (2004) also indicate that when government provides assistance, registration is not comprehensive as only a few households could be assisted, leaving many needy households without assistance.

Thus, some grandmothers resorted to selling homemade beer or fruits to generate income. The extended family as the traditional social security system in many African countries has been weakened because parents, aunts, and uncles are dying of AIDS. In some instances grandmothers end up caring for children from polygamous marriages. Due to the high mortality rates and the weakening of the extended family, the burden of caring for orphans is left entirely on grandmothers (Matshalaga, 2004).

2.4. Coping Strategies

Due to lack of access to additional income, elderly seek alternatives in instances where they have to transport a sick person to the clinic or hospital. Many older people resort to selling important assets to pay for medical expenses (Knodel, 2006). This is further supported by, the Commission on HIV/AIDS and Governance in Africa (2009:p. 15) which states that “income is lost and assets are sold or rented in order to get cash”. It becomes even more difficult in poor communities, where the elderly have no worthwhile assets to sell. The elderly may be forced to reduce expenditure on basic commodities and to spend their income on medical treatment expenses. One of the alternative methods usually adopted is a reduction in the purchases of clothes and food. This state of destitution may lead to an undesirable situation with children being withdrawn from school or their school entry being delayed in order to save money for treatment. The survey also indicates that in half of the cases in which a parent gave care to the ill
child, one or both parents had to either stop or reduce their economic activities (Knodel Zimmer, Kim & Puch, 2003).

2.5. The State of Older People in Ethiopia: A brief overview

The term “elderly” has different meanings in different parts of the world. It can be associated with chronological age, health and function age, or retirement age. The United Nations defines old age as sixty and above. The retirement age in Ethiopia is also sixty (MOLSA, 2004). It is estimated that 4.8 percent (3.6 million) of the total population of Ethiopia in 2007 will be older people above the age of 60 (CSA, 2007).

Older people traditionally enjoy respect, consideration and support among the diverse cultural groups in Ethiopia. They are recognized for their wealth of experience and for their important roles as teachers of moral values, leaders of religious institutions, traditional medicine experts, and traditional birth attendance experts, chairpersons of social courts and community affairs, mediators of conflicts, literacy skill educators and marriage counselors and mediators (MoLSA, 2005).

The constitution of Ethiopia, Art.41 No.5, recognizes the rights of older people and stipulates that “the state shall, with available means, allocate resources to provide rehabilitation and assistance to the physically and the mentally disabled, the aged, and the children who are left without parents or guardian”. The Ministry of Labour and Social Affairs is the primary government organ charged with ensuring the welfare of older people in Ethiopia. The Ministry has set up the Department for Aged People and developed a Developmental Social Welfare Policy, Plan of Action on Older People and an implementation manual to advance and protect the
rights of older people. It also provides technical and administrative support to NGOs, associations and individuals working for older people. The Ministry is currently developing a national social protection policy to reduce social and economic risks, vulnerabilities and deprivations.

Services provided to older people by the government include institutional care, financial subsidies and a retirement pension. Institutional care was started during the reign of Emperor Haile Selassie in the 1960s and primarily targets older people who cannot support themselves because of advanced age and lack of family support. Altogether the government set up three old people’s homes. One of the homes was established in Kaleti, located in the town of Akaki, on the outskirts of the eastern part of Addis Ababa. The second is Bethesel Home for the Aged, located at Debre Libanos, in Oromia Region and the third is Abraha Bahta Home for the Aged, located in Harar, in Harari Region. All of the centers provide basic necessities: mainly food, shelter, clothing and free medical care and have benefited approximately 500 destitute older people (Assefa, 2008). Another service provided by the Government of Ethiopia was the subsidy provision, which was introduced around 1996 to augment the meager income of 350 families of older people (UNFPA/ The Rehabilitation Agency, 1996). The government provided about 50-60 Birr per month to destitute older people who had no regular income or support from other sources. However, the subsidy system was suspended due to insufficient resources and the complexities of implementing the programme. A lack of effective targeting was also considered a barrier to the smooth implementation of the subsidy system. The government retirement pension is the largest social security scheme in the country and covers 650,000 retired government employees who served in the civil, public and military services.
In addition to the government, there are over 80 non-governmental agencies working around issues affecting older people (MOLSA Directory, 2010). However, most of them are concentrated in Addis Ababa (31 NGOs) and regional or zonal capitals. Their key services include the provision of food, medical help, indoor games, clothing and some provide income generating activities. Some of the NGOs have also extended home based care to bed bound destitute elders by mobilizing active elders to help take care of their fellow older people.

In spite of the above mentioned interventions, older people are living in destitution and their living conditions are becoming worse due to the weakening of traditional family support mechanisms especially in urban areas. Existing evidence shows that older people often fall into the extreme poverty category and they cannot afford basic health care, social services or housing. They face discrimination and generally lack social protection (Assefa B., 2008).

The vulnerability of older people to disasters and conflicts is high. Most health care providers in Ethiopia do not know about the health needs of older people. Older people also face the risk of contracting HIV either directly or through a care giving role, and often lack knowledge about HIV & AIDS. They continue to be excluded from HIV prevention and HIV & AIDS care and treatment services. As these examples of the challenges currently facing older people in Ethiopia clearly demonstrate, the specific requirements of older people must be included in government services and policies (HelpAge International, 2009).
Summary

This chapter has shown that older people are carrying a huge burden because of HIV/AIDS. In the fight against HIV/AIDS elderly people have constantly been ignored, yet are suffering. This chapter has identified a number of difficulties encountered by the elderly when caring for AIDS orphaned children in their households. A number of studies reviewed in this chapter show that the impact of HIV/AIDS on the elderly has been largely neglected. The chapter discusses the role of the elderly becoming parents again by looking after their grandchildren. The chapter further states some of the coping strategies the elderly often adopt to cope with the situation. Lastly, this chapter highlights the state of older people in Ethiopia and some of the measures that have been undertaken by governmental and nongovernmental agencies to mitigate the problems of older people in the country.
Chapter Three

Conceptual Framework

This research is informed by two models, the psycho-socio-environmental (PSE) model and the ABC-X model of the family stress model. The PSE model provides an overall explanation for the multiple impacts of HIV/AIDS on elderly women while the ABC-X model shows the connection between adult HIV/AIDS related illness/death, perception of care giving role and their impact on elderly caregiver’s well-being.

3.1. Psycho-socio-environmental Model

This research is informed by the psycho-socio-environmental (PSE) model which focuses on how health is promoted and maintained through socio-environmental and behavioral factors (Gilbert, Selikow and Walker, 2002). The PSE model puts health maintenance and disease causation in a broader context by focusing on other factors such as social and environmental factors, rather than biological (or medical) factor only, as their determinants. It is complementary to the bio-medical model which considers health and disease only within the biological (medical) context (Gilbert, Selikow and Walker, 2002; Taylor and Field, 2003).

The PSE model provides an explanation for people’s behavior, the work they do, and the place they live as important determinants of their health status (Gilbert, Selikow and Walker, 2002; Gabe, Bury and Elston, 2004). In other words, other factors such as social and environmental factors and not only biological factors influence how healthy people are. The model, therefore, puts health and disease —in a social context which takes a macroscopic view and offers a broader perspective‖ (Gilbert and Walker, 2002a: 652). Figure 3.1 explicates how
the PSE model is applied to this study of HIV/AIDS impacts on elderly women who lost an adult in their household to the epidemic. The diagram (figure 3.1) shows the connection between adult HIV/AIDS morbidity and mortality and five main impacts experienced by elderly caregivers and their households.

Figure 3.1: The application of the psycho-socio-environmental model to the study
Using this adapted PSE model, the framework (figure 3.1) serves as the conceptual framework for this study. The link between adult HIV/AIDS related morbidity and mortality and the concepts of demographic, socio-economic and socio-cultural impacts experienced by elderly caregivers and their households is explored in this thesis. As a result of the need to have a better understanding of these concepts, each concept and its link with adult HIV/AIDS related death is examined individually. For the purpose of this thesis, the concepts are defined as follows:

Demographic impact— is the occurrence of headship caused by the absence or death of an adult in elderly caregiver’s households.

Socio-economic impact— refers to the financial crises experienced by elderly caregivers who had an adult illness/death in their household as well as the effect of the incident on their socio-economic status.

Socio-cultural impact— refers to elderly caregiver’s experience of secondary stigma, which may be rooted in some cultural beliefs in their community.

3.2. Family Stress Theory

In order to further explain the connection between adult HIV/AIDS morbidity and mortality and their impacts on older caregivers to AIDS orphaned children and their households, with a particular focus on family’s adaptation to change, this study is informed by the ABC-X model of family stress theory. The theory was first developed by Reuben Hill to explain the response of families to stress and their adjustment to the crises of war separation and re-union. This theory also serves as an explanation for the changes that occur in families/households because of life transitions and events such as migration, divorce, illness and death (Smith, Hamon, Ingoldsby & Miller, 2009).
The family stress theory has been used by authors in different fields, such as Sociology and Medicine, to explain how members of a family are affected when an event such as a chronic illness, disability or death befalls someone (Perry in Ogunmefun, 2008). The theory was also used by these authors to explain how family members, who are caregivers to the sick, experience difficulties or stressors which have impacts on their lives (Ogunmefun, 2008).

As aforementioned, the family stress theory was first proposed by Reuben Hill in his research on families and stressors of war separation and reunion. Using this theory, he formulated the ABC-X model, where:

- **A** – The provoking event or stressor
- **B** – The family’s resources or strengths at the time of the event
- **C** – The perception or the meaning attached to the event by the family
- **X** – The outcome: the resulting degree of stress or crisis (Smith, Hamon, Ingoldsby & Miller, 2009).

The ABC-X model of family stress theory states that, A (the event) interacting with B (the family’s resources) interacting with C (the definition of the event by the family) produces X (the degree of stress or the crisis).

The application of the ABC-X model of the family stress theory to this study is shown in the diagram below. A, B, and C factors are inter-connected and they are linked to the X factor. The A factor is the event that occurred in an older people’s household as a result HIV/AIDS; the B factor is the older caregivers resources or strengths to cope with the event; the C factor is perception of care giving role; the X factor is the degree of stress or crisis, i.e., HIV/AIDS.
impact. The A, B and C are factors that work together to produce X. This study examines how these factors interact and cause the impacts of HIV/AIDS on older caregivers to AIDS orphaned children in their households.

Note: A= death of an economically active adult member; B= older caregivers resources or strengths to cope with the event; C= perception of caregiving role; X= HIV/AIDS impact

The above figure shows the inter-relation between the A, B, C, and X factors in this study of HIV/AIDS impacts on older people and their household. This study, therefore, has utilized the ABC-X model of family stress theory as one of the potential explanations for the crises that occur in an older people household when an economically active adult dies of HIV/AIDS and their burden of raising their grand children.
Chapter Four

Research Method

4.1. Study Area

The study area is located in the western edge of Addis Ababa. It is considered as one of the semi-peripheral parts of the city known for its informal business activities. According to the former administrative structure of Addis Ababa Kolfe encompasses Kebele 9, 10 and 11 from Woreda 24 and Kebele 3, 4, 5, 6, 7 and 8 from Woreda 25. Kolfe is included in the Kolfe-Keranio Sub-City Administration. According to the records of the sub-city administration, the total population of the sub-city was estimated at 428,654 in 2010.

Geographically, Kolfe covers locations stretching from the Dutch Embassy to the General Wingate High School area. The General Wingate area in the north, the Mesalemiya area in the east and the Torr-Hayloch area in the south border Kolfe. The Kolfe area is subdivided into a number of neighborhoods called Sefer and the residents identify the small physical units by different names. The most famous ones include Atena Tera, Lekuanda, Taiwan Chereta, Mekonnen Habtewold Forest and Soramba.

4.2. Study Design

The study employed qualitative design and has descriptive nature. Qualitative inquiry is best suited for a type of question which is best understood through a detailed account of several individuals’ common or shared experiences of a phenomenon (Cresswell, 2007, p.80). As Punch (2000,p.8) and Creswell (2007,p. 54) stated qualitative research is important when we need a
detailed understanding of the issue and this detail can only be established by talking directly with people and allowing them to tell the stories unencumbered by what is expected to be found. In addition, as Corbin and Strauss (2008, p.12) note, “qualitative research allows researchers to get an inner experience of participants … to discover rather than test variables.”

Thus adopting a qualitative inquiry in this study is based on the justification that the underlying questions of the study are best understood using this approach. The research questions in this study call for an in depth understanding of the issue so that a good detail can be developed to answer them. The research questions in this study basically focus on what is the living condition of older care givers to AIDS orphaned children. The general character of the study will be concerned with description of facts and characteristics concerning this group and their situation. Thus qualitative research is well suited to understand and examine complex social phenomena like that of AIDS induced problem of older people. In addition, there is insufficient and reliable data concerning the number of older care givers in the study area. Hence, due to the nature of the research question, complexity of the topic of study and lack of readymade and reliable data in the study area, it was found necessary to use qualitative approach with a descriptive purpose by using different interview techniques such as in-depth interview, focus group discussions, and direct observation to gather first hand information.

4.3. Sources of Data

Data were gathered from primary and secondary sources.

Primary sources: the primary data were collected from in-depth interview and focus group discussion conducted with older care givers, interview with governmental organizations and
nongovernmental and observation made on the living arrangement and condition of older caregivers.

*Secondary sources:* To supplement the primary data, government policy documents, different books and research reports written on older caregivers were used. In addition, other sources both published and unpublished were reviewed and referenced to enrich the study.

### 4.4. Methods of Data Collection

Three techniques of data collection were employed for this study. First, interviews with the two groups of participants (older caregivers and officials from concerned governmental and nongovernmental organization) and focus group discussion were conducted and observation. The interviews and FGD were conducted in Amharic.

*In-depth Interview:* The study made use of open-ended semi-structured interviews, which were in-depth in nature and allowed me to explore the topic of interest more openly, while allowing participants to express their opinions and ideas in their own words (Esterberg, 2002). A total of 9 individual in-depth interviews were conducted in the study area. The interviewees were recruited among elderly caregivers who are currently taking on the parenting role of AIDS-orphaned children. Only two males met the requirements and took part in the interview. I conducted the interview by entering the setting with the necessary care and engaging with the older caregivers in an open and empathetic manner, given the sensitive nature of the topic. The interviews lasted one hour on average. The interview is believed to best suite the investigation of what the living condition of older caregivers experience is, in terms of the conditions, situations, or context, their attitudes and thoughts.
Focus Group Discussion: The second method of data collection was focus group discussion (FGD). One focus group discussion, consisting of older caregivers to AIDS orphaned children as participant was conducted. The focus of the FGDs was important to cover the underlying reasons behind the problems faced by older caregivers, to identify the coping mechanisms used by older caregivers and resources available which help them to cope with the challenges they face.

Interview with concerning governmental and NGO representatives: With regard to inputs from other sources, a topic guide has been developed and interview informants from relevant governmental organizations and institutions working on the issues under consideration, including Ministry of Labour and Social Affairs and HIV/AIDS Prevention and Control Office. This was important to get more insights about the situation of older caregivers to AIDS orphaned children and the measures that have been undertaken to mitigate the problems of older caregivers.

Some observations: Most interviews were conducted on a face-to-face basis at the homes of caregivers. This setting presented two-fold advantages. Firstly, the interviewees did not have to stop their normal activities. Secondly, it allowed the researcher to make more observations of the “world” of caregivers.

4.5. Research Participants

Participants of the study were older people aged 60 and above, who care for HIV/AIDS orphaned grandchildren. The study was conducted in Kolfe Area including Woreda 10, 11 and 12 of Kolfe Keraniyo Sub-city, the area where the prevalence of HIV/AIDS is very high. The mean age of the respondents was 63 years. None of the participants were employed during the time of the interviews. However six were involved in activities in the informal economy (for example, selling fruit and vegetables). In addition, four participants were receiving an old age pension. All
of participants were living with more than one grandchild and others were living with extended family relatives. A total of 9 older caregivers (3 from each woreda) were participated in the in-depth interview and 7 older caregivers (6 female and 1 male) participated in the FGD. In addition, representatives of governmental organizations including MoLSA and a local NGO named Tesfa Social and Development Association was also participated in the study.

4.6. Sampling Procedure

Participants were selected using non-probability, purposive sampling which emphasizes that sampling should be done for information-rich cases. In other words, the researcher purposively selected respondents and informants according to their relevance. It involves the researcher in handpicking subjects on the basis of traits to give what is felt or believed to be a representative sample (Patton, 1990, cited in Merriam & Associates, 2002). The small sample size was chosen as it allows for the development of contextually-rich narratives that would deepen an understanding of the study’s inquiry. The main advantage of this sampling method is that one can possibly better ensure a cross-section of the population in a small sample (Black, 2002).

However, I acknowledge that I may not have identified all contributing variables and characteristics, and that individual bias may have prevailed when carrying out the selection. Identification and selection were facilitated with the assistance of the Kolfe Keraniyo Sub-City’s Labour and Social Affairs office, Tesfa Development Association and some local gatekeepers, including resident’s forum leaders. The criteria for choosing participants were that they should be permanently living in the study area; their age needs to be 60 years and above and they should be caring for their grandchildren who were double orphaned by AIDS. This requirement posed a
problem as some older care givers wanted to be included on the basis that they had cared for orphans. Because of the overwhelming numbers of orphans in the study area, older caregivers are struggling and are therefore, eager to explore any possible source of assistance. Although I had made it clear that there would be no direct benefit resulting from participation, potential participants nevertheless, hoped that it might somehow help them deal with their care giving burdens.

Furthermore representatives from MoLSA were participated on the interview because it is the main government Ministry mandated with the designing and implementation of policy frameworks to enhance the welfare of older people in the country. On the other hand representatives from Tesfa Social and Development Association participated on the study as it is the main nongovernmental organization with a vast experience of intervening in the area to improve the living condition of older caregivers and their families.

4.7. Data Analysis

All the interviews made were tape recorded and field notes were taken during the interviews. Then data were classified as per the research question of the study. After, data were transcribed and translated into English as the interviews and FGD conducted in Amharic. This process was followed by coding, the purpose of which is “to get from unstructured and messy data to ideas about what is going on in the data” (Morse & Richards, 2002, p.111). It also allows the researchers to simplify and focus on some specific characteristics of the data. The topics which participants talked about served as important base for coding. Out of these codes, thematic areas were developed which refers to labels given to discrete phenomena (Bryman, 2004). Thematic analysis was then applied where, after extensive reading of the material, major categories/
themes and subthemes were developed. During the analysis stage, I identified the major themes and then recorded them into different sub-headings or categories to make it easier to compare similarities and differences. These were organized around the main four question areas.

4.8. Ethical Considerations

The study has followed a standard and scientific procedure of doing research in such a very sensitive topic. Accordingly, a letter of cooperation from Addis Ababa University School of Social Work has been read to each participant of the study in the language they understand and they were introduced first about the purpose of the study.

Informed consent was sought prior to the interviews. The informed consent form - translated into Amharic- was read to individual interviewees before interviews to let them know what their rights were and the interviewees were asked to sign this form. Every effort was made to ensure that participants understood what was expected from them. They could ask questions at any time during interviews. Further questions were asked to make sure that their rights were not infringed upon or that they were not frustrated or embarrassed before proceeding with the interview. Then informed consent from respondents and relevant officials of the institutions which were covered in the study was obtained to discuss with and interview them.

In order to ensure the confidentiality of every caregiver that participated in this project, their name was not mentioned during data analysis to protect their identity. Besides some of the personal questions that were in the interview guide, none of the participants were asked to disclose their HIV status. Even if such information was willingly provided, it was not included in
any chapter of the study. The data collected for this project cannot be used for other purposes without the participants consent.

4.9. Trustworthiness

The data gathered were trustworthy as the study utilizes multiple sources of data including in-depth interviews and focus group discussion conducted with older caregivers, direct observation and interview conducted with government and nongovernmental office representatives. This was further supported by recent studies carried out in Ethiopia and some developing countries such as South Africa, Zimbabwe, Kenya, Uganda and Thailand on the elderly who are caregivers. I also made use of recent information available from the internet and publications from the WHO, UNAIDS and HelpAge International. In addition, to ensure the trustworthiness of the study, the interviews and FGD were only conducted by the principal investigator of the study in order to maintain a high quality of data. All the interviews and the FGD were tape recorded and field notes were taken during the interviews for key points. This helped to ensure the trustworthiness of data.
Chapter Five

Findings of the Study

This section deals with the presentation of data obtained using different techniques of data collection. Four main themes arose in the process of analysis. These themes are: (1) responsibilities of older care givers as care providers to AIDS orphaned children (2) challenges experienced by older people in caring for AIDS orphaned grandchildren, (3) coping strategies and (4) resources and support systems available to assist older caregivers in caring for AIDS orphans. But first the general characteristic of respondents is discussed as follows.

5.1. Socio-economic and Demographic Profile of Participants

The socio-economic and demographic profile of participants of the study is indicated in the following table:
Table 1. Socio-economic and Demographic profile of Participants

<table>
<thead>
<tr>
<th>No</th>
<th>Items</th>
<th>FGD participants</th>
<th>In-depth Interviewee</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>a. Male</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>b. Female</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>2.</td>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>a. 60-65</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>b. 65-70</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>c. 70-75</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>d. 75+</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>3.</td>
<td>Educational Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>a. Unable to read &amp; write</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>b. Able to read &amp; write</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>c. Primary education</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>d. Secondary education</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>4.</td>
<td>Marital status:</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>a. single</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>b. married</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>c. separated / divorced</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>d. widowed</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>5.</td>
<td>Family size</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>a. 0-3</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>b. 4-6</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>c. 6 and above</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>6.</td>
<td>Means of survival:</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>a. pension benefit</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>b. petty trade</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>c. family support</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>d. NGOs support</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>e. cottage industry/small business enterprise</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>7.</td>
<td>Housing condition:</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>a. rented/kebele home</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>b. private/own home</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>7</td>
<td>9</td>
</tr>
</tbody>
</table>

Source: Own Survey (May, 2014)
Table 1 outlines the socio-economic and demographical profile of the elderly caregivers participated in the study. As indicated in the table the total number of participants of the study is 16, of who 2 were men where as 13 were their counterparts. When we look at participant’s age structure, 5 of them are aged between 60 - 65, while 5 of them are aged between 65 - 70 and 4 participants are aged between 70 – 75 and the rest 2 participants were aged 75 and over.

Concerning their level of education, 6 participants are unable to read and write; 5 were able to read and write; 4 participants have attended primary education and only one participant has attended secondary education. In the same table, item four indicates marital status of older persons participated in the study. Accordingly, 1 participant was single, 5 participants were married, 1 participant was divorced, and 9 participants were widowed. As could be seen from item six of the same table, the family size of the majority of the participants ranges from 4-6.

However, there are also considerable number of older persons whose family size is above six. As shown in the same table, the main means of livelihood for older persons include petty trade, pension benefit, family support, NGOs support, and involvement in cottage/small business industries. Regarding their housing condition, it was documented in this study that 15 out of the total 16 participants elderly are living in rented/kebele houses and only one older person live in his own house.

5.2. Perceived Roles of Older Careers in Caring for Children Orphaned by HIV/AIDS

In this study, older caregivers were found to carry out a wide range of care activities. Elderly caregivers took on the parenting role of AIDS-orphaned children whose ages ranged from early childhood to late adolescence. They felt responsible for meeting the needs of their
grandchildren and other dependents and provide food, clothing, and education, medical and emotional support. Apart from the responsibility towards their grandchildren, five elderly reported that they had to take care of themselves as well as their spouse in every way. These include doing household chores, such as cooking, cleaning and laundry, also seeking medical treatment and supporting each other. All elderly participated in this study were also the primary breadwinners in the household. Their most important source of income was their pension benefit, income generated from petty trade and some of them received money from their surviving children to supplement the family income. One participant said the following:

I am taking care of two orphan children. Their father and mother died four years ago. I wash, feed and also send [them] to school. My daughter, the mother of these children, died so I have to take care of them. When they are sick, I take them to hospital. I also buy clothes for them (participant-1)

The number of orphaned children cared for by the elderly is variable. Prior to the illness and passing away of their biological parents, some children were already under the care of their grandparents. However, the death of parents has made it necessary. They do not see themselves as substitute parents or caregivers but as biological parents to the children. The following participant talks about her experience:

There is not much difference because I have always played the mother role even when her biological mother was alive. I was the one that gave her love, I would defend her when her mother hits her, and I would tell her that hitting a child does not build them. Also she called me mother and called her biological mother by her first name.

(Participant-12)
In relation to this an elderly who was taking care of her two grand children said the following:

In actual fact the children I live with are my daughter’s and the community has always known them as mine, they call me mother. So luckily they do not have a reason to see themselves as orphans, so much so that I do not want them to even think that they are orphans because I am still alive and I am taking care of them. (Participant-9)

The elderly caregivers reported having to tend to the needs of their school-going grandchildren with respect to fees, food, clothing, and medical needs. Participant 2 stated that: “I have to buy food for the house, send children to school, and pay their school fees and uniform”. Similarly another participant said “I have the grandchild who is at school, I am supposed to wake up early in the morning and follow that she eats and she is neatly dressed. When I am done, I have to prepare lunch so that when she comes back from school she gets food” (participant-4). Likewise another participant said “I buy them food and their school uniforms; they never sleep on an empty stomach” (participant-5)

Those participants who were taking care of very young grandchildren had to wake up at irregular hours and provide care for babies in the middle of the night, as well as washing, feeding and changing them. Furthermore, the elderly indicated to feel responsible for the emotional well-being of their grandchildren, as one grandmother states “Even when they are back it is the same thing: How is your homework, what happened at school today and what did you do.” – (participant-6). Another participant who was taking care of her two grand children said “I talk to them, give them hope when they are feeling hopeless, I encourage them to pray and instill that belief that God will pull them through” (Participant-1).
The presence of older children in the household can be of great help to elderly caregivers since they are able to perform some domestic tasks and ease the burden of care giving. The elderly inculcate the sense of responsibility among AIDS orphans as they are able to take some initiatives and avoid relying on others. Hence, orphans are not always passive care-recipients but also active household members since they can provide crucial assistance to the elderly in case of illness or other situations that arise. Caregivers are expected to perform every task for younger children but once they grow older, the elderly become less involved in their daily care. The following participant highlights her experience:

I thought these children to be independent and know how to do things themselves. I just monitor them to ensure that they are on the right track. For instance, they wash their own clothes. I believe they are old enough to do it themselves apart from my four year grandson. But for main meals I cook for them. Honestly speaking, I do not do too much for them and they are well trained when it comes to do things on their own. (Participant-7)

Older care givers who participated in the FGD stated that providing basic needs for children under their care was the major role they played as caregivers. Basic needs include food, shelter, clothes, education and health care. Another role mentioned by the caregivers was providing school material and paying school fees. FGD participants cited the role of providing guidance and counseling for children to be good citizens by encouraging them to be disciplined, respectful and responsible people, teaching morals and ethics, not to behave badly in schools and other places. Teaching children cultural norms and values also mentioned by older care givers.
Other important role stated by FGD participant is related to life skills, which include introducing children to domestic work and small scale businesses, and showing them love and affection by being mother and father to the children. Meeting emotional and spiritual needs of the child as religious mentorship was also cited by FGD participants.

5.3. Challenges Experienced during Care Giving

The major challenges facing elderly caregivers who participated in the study can be categorized into economic, health and psychological,

Economic Challenge

A major difficulty cited by older caregivers who participated in the study was lack of income and resources. The impact is that older care givers cannot cover basic needs like food, clothes, education and health care. This is also aggravated by the rising cost of living in the country. An elder woman caregiver who participated in the in-depth interview said:

My main problem is food and clothing for the children. They are growing fast and need food and clothes repeatedly. They also need support to attend school. Moreover, I have also one grandchild who is with physical disability who is not also mentally stable. Overall, life is becoming very miserable so that I prefer dying than living such a miserable life. (Participant-8)

In relation to this another participant said the following:

I rely on the pension grant I received from the government. However, the amount of money I am receiving is not enough to meet the needs of all my family. With the little
money received from the government I have to buy food for the house, send children to school, and pay for their school fees and uniform. (Participant-5)

The death of economically active member in the household has brought immense economic challenge to older care givers. Food, clothes, soap, and blankets were cited as scarce commodities in the household of these older caregivers. One participant has the following to say:

My daughter was the only one who was working in this house because her father stopped working long time ago. My daughter used to work in one of the factories in Addis Ababa and she was very supportive, unfortunately when she suddenly became very sick there was no way that she could continue with her work because she was very weak and she was missing a number of days at work so the employer would not give her salary when she was absent from work (participant- 3).

In relation to this another participant stated the following:

Ever since my son passed away it has been very difficult, he was the only one who managed to bring something to the family, and the income I get from the pension is very minimal and insufficient to fulfill the basic needs of the family. We sometimes rely on neighbours to assist us with some money for food and return it back whenever I get the money (Participant-10)

Older care givers who participated in the FGD indicated that they are not able to fulfill basic needs of the children under their care, and properly undertake their care giving role because of limited source of income. They are not able to feed the children properly and they worried this was affecting the children’s growth and development. Some caregivers who participated in the FGD ended up wanting orphans to drop out of school to alleviate their burdens. This can best be
described in one discussant’s expression: “Since last year, I have been begging my grandchildren to drop out of school to ease the heavy burden I have, but she would refuse and cry continuously.”

Lack of time to engage in productive work due to care giving burden and ill health and physical condition contributed to financial pressure according to an older woman participated in the FGD. Other participants of the FGD also mentioned that being too old and frail to care for the children and mobility problems make it difficult to undertake their responsibility effectively.

FGD participants further said that being a full time caregiver to grandchildren had far reaching economic implications for them. Three older caregivers relied on aid from Non-Governmental Organizations (NGOs) that are intervening in the area such as Tesfa Social and Development Association and World Vision Ethiopia. Those who are fortunate to be enlisted for this aid, however, complained about delays and inadequacy of assistance being provided.

Health and Physical Challenge

Participants of the study stated that their health compromised their ability to provide adequate care for their grandchildren. They said that care giving aggravated their poor health condition – they complained about diabetes, hypertension, side pains, backache, painful legs, and tiredness and reported having health problems either from re-parenting at an old age or because of the stress suffered as a result of losing a child or children to AIDS. Among the participants two of them had hearing problems, two were on treatment for Tuberculosis (TB), five are diabetic and five of them experienced visual problem. It was also observed that most of the study’s participant older care givers are in an ill physical and health condition.
Most of the health problems were cited as a result of old age, excessive responsibility in caring for the orphan and other family members as well as hard work since most of their work is manual and routinely done. One older female respondent describes how her ill health is affecting her caring capacity as follows: “my back, knees and eyes give me trouble; I believe this occur to old age. I can barely see as we speak.” (participant-6). Similarly, another participant said “my main problem is that I cannot walk properly; I cannot walk for long distances alone. One of the girls helps me. The problem is that I am alone with these children and due to my sickness I send them to get my medication for me”. Another participant also said “I’m not ok, just this morning I needed a massage because my back hurts. I have also diabetes and high blood pressure”.

However, without taking into consideration their poor health and physical condition, older caregivers starved and even deprived themselves of some material needs in order to please their care-recipients. The experience of the following participant described this situation: “I give them all the love I have. Even when I am eating somewhere I always think of them and instead of eating the food I bring it home for them”.

*Psychological distress*

Participants stated they are experiencing psychological distress because of the losses they incurred and the burden of caring for orphans. They raised concerns about what the future holds for them, given the young ages of the orphans they cared for in relation to their feeble bodies. They are worried about what would happen to the orphans if they themselves were to die. With regard to this one participant said “Now I am old and taking care of my grandchild. What if I die now? I don’t know who is going to take care of the child”.

The secondary stigma associated with HIV and AIDS in their community is another main cause of emotional stress to older caregivers. Regarding this one older care giver said the following: “Other children used to harass him not because they knew he is HIV positive, simply because they know that he is sick and weak and could not defend himself. What hurt me most is that some of the neighbours used to gossip about him, saying he is HIV positive and that is why he is having a big head” (participant-3)

Older care givers who participated in the FGD indicated that lack of income and resources and dealing with parenting issues including addressing behavioral, emotional and psychological issues of their grand children as major difficulties they face as care givers. Other major difficulties were physical weaknesses, lack of community and family support, stress and depression.

An interview conducted with representatives of MoLSA and FHAPCO and Tesfa Social and Development Association indicated that socioeconomic status of the deceased parents, socio-demographic and economic situations of caregivers [lack of income, age and health conditions] as well as ineffective interventions of the stakeholders as the major factors aggravating care giving responsibilities for and survival problems of the older care givers. They further reported that the existing social welfare system and policy frameworks did not adequately address the problems of older care givers to children orphaned due to HIV/ AIDS. In addition, they reported that weak social and economic development of the country incapacitates the government to provide adequate support and undertake effective interventions.
The challenges faced by the elderly caregivers negatively affect their responsibility and competency as care providers. FGD participants also described that in addition to their socio-economic problems, lack of caregiver targeted programs of governmental organizations and NGOs; inadequate care and support by the government overburdened of care giving responsibility for these additional children without any income or support. One discussant said that:

What happened to us is already happened and passed but we do not want our children to be troubled even pending our death, however, they are suffering a lot because we have no income, we are ill, we are not assisted well by the NGOs, community and the government in particular to fulfill the survival needs of these children. All these situations are aggravated by the stigma we are facing. It is crisis for our living condition. (Participant-5)

In addition, from the observation of living condition of some of older caregivers, it was found that orphaned children, particularly those who are managing their life as heads of the household have severe problems of clothing, food, and shelter- dilapidated homes.

5.4. Coping Mechanisms

This study found that elderly caregivers were using various strategies in order to cope up with the difficulties they face as care providers to their grandchildren. Those participants who are struggling financially opt to borrow money from friends, neighbours and the like in order to cope with the demands of caring for the orphaned grandchildren and other basic household commodities. Four participants felt that they were bothering their neighbours by continually borrowing money from them. The following participants provide more insights into this issue:

“Whenever the situation goes beyond my power I borrow the money from neighbours and pay
them back when I get my pension‖ (participant-7). Similarly another participant says “If I do not have money I borrow from my neighbours and in some cases even my neighbours do not have money themselves” (Participant-4).

There were six participants who engaged in additional tasks to further supplement the family income as illustrated by one of the participants: “I need to work so as to increase the pension money. I sell injera I was able to make some profits and have saved some money. (Participant-6). Similarly another elderly care giver who started a small business with the help of TSDA said the following:

Tesfa had given me startup capital to start and expand my business, after I told them that I am a street vender. They gave me various items worth of 2500 Et Birr. That is how the kids and I have been surviving. I have used the startup capital to increase the goods that I sell on the side of the street. Thanks to God, I was able to save some money. In addition to the startup capital, the organization has also offered training on business skills for me and other elderly caregivers who are doing small businesses in our community, (Participant -2)

The main ways mentioned by older caregivers participated in the FGD as a coping mechanisms were undertaking small scale trading and engaging in other income-generating activities such as casual labour. Additional ways which were mentioned include using resources wisely, reducing food consumption, selling assets, burrowing money and remittances. Among the small scale trading mentioned by respondents include simple trading and selling vegetables income petty trade. This finding is also supported by the observation made in the study setting.
Seeking support was another way FGD participants mentioned to address their challenges. This include a variety of approaches such as developing close relationship with and asking for support from relatives, community members, civil society organizations, local government and well-wishers.

With regard to dealing with emotional distress of parenting, participants mentioned their religious beliefs as a source of their comfort and strength. They maintained that they regularly attend church and prayed more often so as to lighten their burdens. Most of them believed that what they are experiencing is God’s will. Their religion and spiritual life, therefore, serves as their source of strength.

Interviewees from MoLSA and TSDA described their experience regarding, “how the older caregivers coping with the challenges they face?”, by saying: “Some individuals and community share their limited resource with the older caregivers and their families while those individuals and community, whose attitude and awareness about HIV/AIDS is relatively raised, identify and refer the orphans to the institutions supporting older caregivers and AIDS orphans while those community members whose awareness was not yet changed are kicking out the older people from their home or community organizations like iddirs”.

5.5. Available Resources and Support Systems

With regard to the organizations that provide assistance to caregivers or ease the burden of looking after people living with HIV/AIDS, the sick and AIDS-orphaned children, most of elderly caregivers who participated in the study do not have adequate knowledge of any that are functional. They reveal that there is not a visible organization that takes care of caregivers or the
elderly on the ground, however, some make irregular appearances and provide spontaneous assistance before disappearing. It was revealed that the assistance required is not always economic but also advice in the way of handling some tasks or caring for AIDS orphans.

However, some NGOs were reported to be playing an important role in assisting children orphaned due to HIV/AIDS and older care givers. Of particular important is Tesfa Social and Development Association, which helps poor old people in the area. The support scheme includes shelter maintenance, provision of clothing, blanket, bed sheet and food such as cooking oil, wheat, and so forth. In addition, the organization provides saving and credit service to help those older care givers who are able and willing to engage in income generating activities.

Among the participants three of them are getting assistance from TSDA. One older caregiver remarked, “if it was not for Tesfa, I would not have made it through to this day”. However, the mismatch between the need and the support being provided by TSDA was reported as a main challenge. As a result, the organization is only able to support a limited number of needy orphans and older care providers. Representatives of TSDA noted that another challenge the organization have been facing is to strike a balance between assisting poor old people, while at the same time encouraging them to be more self-sufficient so that in the event of such NGOs withdrawing, they would still continue with the most of the community. World Vision Ethiopia also offers educational and health assistance to some households through direct `payment of school fees and food security both at household and community level mainly to orphans and vulnerable children.
Extended family members, friends and neighbours are playing a role in helping affected families to cope with the demands of caring for orphaned children. One elderly woman said she relied on her sister for support because she could not cope with the demands on her household. She said “my younger sister understands my situation and she has been very supportive to me, she phones every day to check how is my daughter doing and sometimes she brought food for us”.

However, four participants stated that they were not receiving support from extended family because their close families were living far away, so they were relying on neighbours for support. One participant said even if she reported her situation to the extended family, they would not bother to visit. The elderly woman went on to reveal that when her daughter passed away most of the extended family members did not attend the funeral. When asked what could be the reasons for the extended families not offering any support or attending funerals the respondents stated: “Maybe it is because they are far, even if I report something to them they do not even bother to come and hear what is the problem” (participant-10). Similarly another participant said “My relatives they stay very far, hence we are not that much in contact” (participant- 12).

Moral support was the major type of support identified by FGD participants which they received from their community. Caregivers who participated in the FGD said that the reason why they do not receive economic support from the community is because members of the community have their own problems in caring for the large number of children and other family
members. However, community members share their burden through talking and giving them moral support.

**Summary of Findings**

This chapter has highlighted the major findings of the study obtained using different data collection tools including in-depth interview, FGD and some observation made at participants living environment. The study has indicated that the elderly are performing various tasks as caregivers to their grand children orphaned due to HIV/AIDS. They are fully responsible to meet the economic, emotional and educational needs of their grandchildren. The study has also found that elderly caregivers are faced with various challenges in providing care to their grandchildren. They are faced with economic difficulties as the income they are getting from pension and other sources are minimal to meet the survival needs of their family members. The death of economically active member of the household is another main factor the economic challenge faced by elderly caregivers. They are also faced with health and psychological problems which arise either due to the losses they incurred, re-parenting or old age. The study further indicated that the elderly are using different strategies in order to cope with the challenges they face. They tried to get support from neighbours, friends and extended family members. Some participants are also engaged in income generating activities to overcome the economic difficulties they face. Finally, the study highlighted the available support systems for elderly in the study area which include support from NGOs, extended family members and community.
Chapter Six

Discussion

The outbreak of the AIDS epidemic has resulted in several challenges that affected the well-being of a particular type of individuals, notably the elderly. They are increasingly playing the role of caregivers to AIDS orphans. This involvement in the daily care of orphans constitutes a major breakthrough but it is not without consequences. This study has highlighted some factors surrounding the care giving activities that have an impact on the economic, physical, emotional and social well-being of the elderly.

This study found that elderly caregivers took on the parenting role of AIDS-orphaned children whose ages ranged from early childhood to late adolescence. The number of AIDS orphans per household was variable. It was found that caregivers are undertaking various responsibilities and perform all the tasks of the household such as cooking, washing, cleaning and bathing children. Likewise, they were expected to wake up early in the morning in order to assist the children to prepare for school, especially the young children. The older ones were able to assist their caregivers in doing some domestic chores, and they only needed some guidance. Besides reducing the amount of pressure placed upon caregivers in terms of domestic tasks, older children were also able to provide assistance to the frail elderly. The elderly are also fully responsible financially and found providing emotional support for the AIDS-orphaned grandchildren. These finding is held true for studies carried out in Uganda and Kenya that revealed that the elderly play a great role in taking care of grandchildren when their parents die. Due to the high mortality rates and the weakening of the extended family, the burden of caring
for orphans is left entirely on grandparents. They support their orphaned grandchildren in poverty, without recognition, and often in poor health (Matshalaga, 2004: P.64).

The study found that there were various factors that impacted on the well-being of elderly caregivers and their families. It was found that the well-being of elderly caregivers was severely affected by several care giving activities. Firstly, they had their own health concerns and were chronically sick for years. Secondly, there were too many care giving activities which made it difficult for them to cope. Thirdly, the elderly were financially burdened and could hardly cope with the demands of an increasing number of dependents. They often refrained from meeting their own needs in order to please other household members. Finally, they were confronting with challenges inherent in the upbringing of AIDS-orphaned children and care giving. The same results were also found in a study aimed to explore how households cope with the HIV/AIDS epidemic. This study found that the elderly are ill prepared for care-giving demands, and overburdened by the enormous financial needs of orphaned children, having been unexpectedly thrust into new roles (Moore and Henry, 2005). The same results were obtained in another study conducted in Zimbabwe, which indicated that at a time in their lives when they might normally have expected to be recipients of care and support, many elderly people have no option but to become ‘Africa’s Newest Mothers (Nhongo, 2004). A study conducted in Kenya, indicates that elderly people who care for AIDS orphans are faced with enormous difficulties. Elderly caretakers face major difficulties in caring for the orphans in terms of schooling, food and medical care. Many older persons are suddenly faced with a situation where they have to resume a parental role and all the responsibilities that go with it, while having no reliable source of
livelihood, and in many cases they do not have the physical capability to undertake such responsibilities (Nyambedha, Wandibba & Aagaard-Hansen, 2003: p.43).

The study also found that older caregivers are faced with psychological distress caused by the loss they incurred and the secondary stigma associated HIV/AIDS. Consistent with this Winston’s (2003) finding, the study established that older caregivers suffer because of the secondary stigma that is associated with an AIDS death, which includes shame, guilt, and anger. The orphans are also in turn, stigmatized – there is no doubt that coping in such circumstances can be difficult or even impossible. Thus, secondary stigma can have dire consequences for those who are affected, like some of the elderly women in this study. The implication of this is that HIV/AIDS related stigma may have long term effect on caregivers, especially in relation to their livelihood which is affected because of stigma. This finding is also consistent with some studies conducted in Africa and Asia have shown how elderly people, who lost an adult child due to HIV/AIDS, experience different manifestations of secondary stigma of HIV/AIDS, such as gossips from community members (Knodel and Saengtienchai, 2002); name calling and rejection at the hands of community members (WHO, 2002).

Consistent with the adopted ABC-X model of family stress theory, the study found that the high prevalence of HIV/AIDS among young people in the study area and the resulting death places a huge socio-economic burden on elderly people. While a parent may experience grief immediately after the death of an adult child, the negative effects of the loss of financial support may not be felt until the elderly parent experiences an economic shock. The present study found that the majority of HIV infected individuals in households were also the breadwinners, thus most households are left with no source of income when the breadwinner dies. Following the
death of their loved ones, it was difficult for caregivers to receive remittances to supplement their income. Some elderly were worried about their well-being and made it clear that caring for orphans was a burden. It was found that they became resentful and were spending sleepless nights if the needs of AIDS orphans were not met. This is further supported by a study conducted in South Africa which found that two thirds of households reported loss of income as a consequence of HIV/AIDS (Henry, 2002:p.2).

This suggests that the elderly are not only enduring the pain of losing a child but their main source of income as well and have to rely solely on the meager income they get from government pension, petty trade, NGO support and the like. A study conducted in the Mpumalanga province in South Africa found that more than 70 percent of elderly people were the breadwinners of households (Makiwane, 2004). Similarly, according to a survey conducted by HelpAge International in Hawassa and Addis Ababa cities, it is estimated that up to 40-50 % of AIDS orphaned children are cared by their grandparents. The study further indicated that little support was available for the older caregivers and they are struggling to meet the basic needs of their grandchildren (HelpAge, 2009).

The present study found that elderly people adopted different coping strategies in order to deal with the ever-growing demands of caring for their grandchildren. Losing such income puts households in a desperate position. Borrowing money from neighbours and engaging in small scale businesses are the main way of surviving when a family runs out money, especially during needy times such as lack of food or to cover school-related fees of orphans. This is further supported by a study that was conducted by Help Age International Eastern and Southern African countries which indicated that elderly caregivers were using various coping strategies
including seeking support from neighbours, friends and NGOs were mentioned as main ways of coping mechanisms to overcome the economic difficulties. This study also indicated that extended family members are playing an important role in providing support for elderly caregivers and their families (HAI, 2011). Another study carried out in South Africa on the elderly caregivers which used focus groups as the data collection method found that neighbours and relatives, particularly extended families, are a good source of support and this includes community organizations such as non-governmental organizations. A small number of elderly caregivers reported being involved in income generating activities such as raising chickens, gardening, sewing, or selling drinks to supplement the family income (Nyambedha, Wandibaa & Aagaard-Hansen, 2003). Nyambedha, Wandibaa & Aagaard-Hansen (2003: p. 43) found that “respondents also reported providing psychological and emotional support to each other by talking about their problems and that appears to provide the elderly with the opportunity to identify with and relate similar experiences, although there are concerns about confidentiality”.

The findings from this study are similar with other studies that have shown the elderly caregivers needed a lot of support to meet their basic needs and those of the orphans under their care. However, little was available from government, NGOs, faith based organizations, the extended family and the community. The elderly lacked information on aid organizations and were often left out when aid was distributed (HAI, 2004).

An overall national development policies, goals and priority areas affect the development of any program or project. The presence of elderly issues in the FDRE constitution, social welfare policies and strategies as well as being a signatory to the international and regional instruments of aging may indicate the government’s recognition to problems of this segment of
the population. However, either being a signatory or the mere presence of policy document does not make sense when viewed from the magnitude of problems of older people. Moreover, both the international and regional instruments of aging recommend states to mainstream issues of the elderly in all development endeavors and thereby take actions accordingly.

Representatives from MoLSA suggest various factors to the inadequate policy repose to problems of the elderly. They pointed out a lack of coordination and the absence of strong partnership among key stakeholders; insufficient budget and resources for respective line Ministries; weak community participation and institutional capacity both at the design and implementation stages of the policy. The rest forwarded poverty as the main obstacle for the unmet needs of the elderly. Discussions with representatives of MoLSA further indicated that HIV/AIDS in Ethiopia affects older people directly as well as indirectly. It has exposed older people to various economic and emotional problems such as poverty and loneliness, through the loss of their children at a time when they were expecting to be cared for and supported by them. In spite of what older people offer by caring for the sick and looking after orphaned grandchildren play the extremely important role older people play in managing the orphan crisis, they are rarely, if ever, included in the policies, strategies, programmes and practices that cater for the needs of orphaned and vulnerable children and hence, there is no considerable efforts as to how to address the problems faced by older care givers to children orphaned due to HIV/AIDS epidemic.
The Conceptual Framework and Major Research Findings

This present study is informed by the psycho-socio-environmental (PSE) model which puts health and disease causation in a social context (Gilbert and Walker, 2002). This model posits that other factors such as social and environmental factors, besides medical factor, are important determinants of the spread of a disease like HIV/AIDS (Gilbert and Walker, 2002; Gilbert, Selikow and Walker, 2002). As noted in chapter 3, the PSE model does not only explain how an infected person contracts HIV/AIDS, but also serves as an explanation of how someone that is associated with him/her (the affected) experiences the impacts of the disease. Hence, the adapted PSE model for this study, posits that the impact of adult HIV/AIDS related mortality on elderly caregivers is multifaceted. In other words, when an adult HIV/AIDS related death occurs in an elderly caregiver’s household, they are likely to experience psychological, socioeconomic, health and socio-cultural impacts of the disease.

The findings from this study are consistent with the adapted PSE model, which provides the overall (theoretical) framework for this study. The findings show that elderly experience multiple impacts of adult AIDS morbidity in their households. The study reveals specifically that elderly experience demographic, psychological socio-economic and socio-cultural impacts of adult AIDS in their households. Some of the findings even suggest that the impacts experienced by elderly women could sometimes be inter-related. For instance, the narratives from respondents suggest that an elderly woman who is experiencing secondary stigma (socio-cultural impact) may lose her source of livelihood (socioeconomic impact). This implies that the impacts experienced by elderly women do not necessarily occur in isolation, as one impact may be
The interconnectedness between the impacts experienced by elderly women is an issue that can further be investigated in future research, as it is beyond the scope of this thesis, as noted in the previous chapter.

In line with the PSE framework, findings from this study explicate secondary stigma as a socio-cultural impact of HIV/AIDS, as narratives reveal how HIV/AIDS related stigma is rooted in the cultural beliefs of the Agincourt community. Hence, elderly women who are caregivers to an infected adult child are prone to the experience of secondary stigma. Furthermore, findings highlight the different forms of secondary stigma experienced by elderly female caregivers such as physical stigma in the form of isolation and separation from family members; social stigma in the form of voyeurism, social isolation; and verbal stigma in the form of gossiping about them, finger-pointing and jeering at them. Narratives, however, reveal that some of the respondents were able to manage secondary stigma by living in denial or ignorance of the status of their loved one. Even though this may prevent the experience of stigma, it may lead to isolation as they would not be able to seek assistance from people with regard to their experience of adult HIV/AIDS related mortality.

In order to further explain the relationship between adult HIV/AIDS related death and impacts experienced by elderly women, the study is also informed by ABC-X model of the family stress theory. The ABC-X model states that the A factor (the event) interacting with the B factor (the family’s resources) interacting with the C factor (the definition of the event by the family) produces the X factor (the resulting degree of stress or crisis) (Smith, 2009). In this study, the A factor is an adult HIV/AIDS related mortality; the B factor is resources available; the C factor is perception of care giving role; and the X factor is the impact of adult HIV/AIDS
related death on elderly caregivers. Findings from the study reveal that the interaction of adult AIDS related death with perception of care giving role and resources available, determines the extent of the socio-economic impact on elderly caregivers. The present study found that the majority of HIV infected individuals in households were also the breadwinners, thus most households are left with no source of income when the breadwinner dies. In other words, elderly caregivers and their family experience of socio-economic and psychological stresses due the provoking event (adult death), the belief that they are bound to be involved in care giving, and the availability of a resources to mediate the crisis. Hence, findings from this study are consistent with the adapted ABC-X model of family stress theory, which provides the overall (theoretical) framework for this study.
Chapter Seven

Conclusion & Implication for Social Work Practice

7.1. Conclusion

As the HIV/AIDS epidemic continues to affect the life of older caregivers, there is a need to support them. They provide care when age-related issues already place a heavy burden on them, and yet they have to act as safety nets for children orphaned due to HIV/AIDS epidemic. The least that we can do is support them as they assume re-parenting in late adulthood. This study supports other studies on older-caregivers that have been conducted in other developing countries like Ethiopia, which report that it is essential to support older caregivers, and that this group not only contributes to the well being of the orphans but also to the community at large, given the weakening of the extended family. The findings, therefore, provide important insights into the experiences of older caregivers, emphasizing their need for social support and the need to be recognized as a group deserving special attention.

7.2. Implication for Social Work Practice

Based on the findings of the study the researcher identifies the following implications for social work practice.

Implications for Community Service Agents

The study has several implications for community service agents who render services to this population. Older care givers high levels of stress and grieving can be alleviated if counseling services are more readily available. The findings further demonstrate the need to assist older caregivers with more insight regarding HIV and AIDS, and in particular, how to
handle the problems they are encountering in their roles as caregivers. Skills training, knowledge, and orientation in raising grandchildren are needed. It is not enough for older caregivers to get financial assistance only; they also need social support and psychological help to strengthen their capacity to continue as caregivers, and to ensure the effective functioning for the future of the orphans in their care. It is also important that aid agencies provide for the basic needs of these older caregivers and be consistent with the services they provide. Agencies should also take greater care to ensure that all areas are covered. Findings also suggest that interventions directed at older caregivers and their families need to take into account the abilities, needs and challenges faced by different types of caregivers, rather than assume that they are the same for all caregivers.

If these recommendations were to be implemented, monitoring in terms of performance and potential would be essential. Community partnership such as involving caregivers and orphans in the implementation and development of the programmes is necessary. This would generate better results than simply design programmes in isolation and hand them over to people in need.

Civil society organizations have a major role to play in supporting older caregivers and children. Hence, CSOs should review their strategies and programmes to reflect a family-centered and caregiver approach to reach older caregivers and children. Older caregivers face significant emotional stress because of their own grief and because of the responsibilities forced on them by the loss of their own children. Psychosocial support targeted at older caregivers needs to put into place to help them cope with the demands of parenting and the responsibilities they face.
The study shows that older caregivers have insights into their lives and circumstances that would enable more effective legislative and programme intervention. They should be involved in designing, implementing and monitoring programmes that concern them. Formal structures and systems should be created for meaningful older caregiver’s participation at local, community and national levels.

**Policy Implications**

The findings of the study revealed multi-faceted developmental implications of HIV/AIDS on the lives of AIDS orphans and caregivers and the community at large. On the basis of the broad findings of the study, the following policy implications can be drawn for various kinds of stakeholders - local, regional, national/federal government bodies, NGOs and other role players.

- The existing legal and policy frameworks should be revised to incorporate issues of older caregivers and effective implementation mechanism should be developed for them;
- Promote community based initiatives through the networking of governmental organizations, NGOs, CBOs, religious groups to enhance the welfare of older caregivers;
- To supplement the coping mechanisms expenditures and fees related to schools, health care services, housing facilities must be subsidized for the most vulnerable older caregivers; empower them with the aim of reducing further risks and vulnerability;
- Promote social and economic support to improve incomes of older caregivers through income generation activities;
- Institutions working with AIDS orphans and local community organizations like CBOs/iddirs must revise their bylaws and regulations so as to make the elderly caregivers
self supportive and protect them from further risks and vulnerability;

- Social stigma and discrimination must be ameliorated by changing public attitude through social mass education campaign;

- The findings of the present study clarified that older caregivers should be incorporated into the social and economic development programs of the country. Based on this fact, for the older caregivers in the city of Addis Ababa, the city administration/municipality, those institutions and CBOs and like have to consider the survival and human rights problems of the orphans and caregivers and incorporate these problems in to their development programs and projects.

**Suggestion for Future Research**

More research is needed to further understand the extent to which the elderly are providing care for their dependents as well as how they are affected by their care responsibilities. More specifically, future research should include theoretical constructs from behavior change theories, such as attitudes, self-efficacy, social norms and knowledge with respect to caring to explain and understand the behavior of elderly as providers of care. Furthermore, forthcoming studies should focus on the psychological impact of care on the elderly and psycho-social constructs such as coping, depression or grief and bereavement, and perceived stigma related to HIV and AIDS should be included. Besides, as the care provided by the elderly has far reaching economic impacts, future research should also include this. Additionally, future research should comprise quantitative information on support available to the elderly, as well as information on quality and availability of services as perceived by the elderly. Subsequently this information should be used to inform the development of supporting structures.
References


Meseret Kasahun (2011). Kinship Care for Orphans and Vulnerable Children in Ethiopia: A


ANNEXES
Addis Ababa University
Graduate School of Social Work
An Assessment of the Living Condition of Older Caregivers to Children Orphaned due to HIV/AIDS Epidemic: the Case of Kolfe Area, Woredas 11, 12 and 13 of Kolfe Keraniyo Sub-City, Addis Ababa
(Interview Guides, Observation Checklists and Discussion Guides)

Introduction

The questions are prepared to collect information and write MSW thesis entitled An Assessment of the Living Condition of Older Caregivers to Children Orphaned due to HIV/AIDS Epidemic: the Case of Woredas 11, 12 and 13 of Kolfe Keraniyo Sub-City, Addis Ababa. The purpose of the study is to assess the living condition of older people who provide care to children orphaned as a result of HIV/AIDS. Moreover, it is intended to assess the existing policy supports and available practices to address problems of older care givers and forward appropriate and feasible social work interventions, which would minimize HIV/AIDS, induced problems of older care givers to children orphaned due to HIV/AIDS in the study area.

In order to attain the stated objectives, collecting relevant and genuine data is highly significant. In this regard, interview guides, discussion guides and observation checklists are prepared to the respective respondents. Accordingly, this paper consists of six sections. These are:

- Section one: Interview guides prepared for older caregivers (Individual cases)
- Section two: Questions and discussion guides prepared for concerned governmental and nongovernmental agencies.
- Section three: Questions to be posed to OVC who are being provided care and support by older people/grand mothers and fathers
- Section four: Discussion guides for FGD participants.
- Section five: Observation checklists
- Section six: Documents to be analyzed
Annex I- Interview Guide Prepared for Older Care Givers

(Individual Cases)

Direction: For each of the following questions, you are requested to provide short, precise and true statements. It is your right to refuse or discontinue from participating in this study. Finally, I would like to assure you that all your responses would be kept confidential and used only for the purpose of this study.

I. Background Information

Code number of the interviewee...............Sex........Age.......Level of education.................
Marital status................Physiological condition........Occupation.................................

II. Family situation

1. Family structure: Extended... ....Nuclear.........Your status in the family..............................

2. Age structure, size and sex composition of the family

<table>
<thead>
<tr>
<th>Age structure</th>
<th>Male</th>
<th>Female</th>
<th>No of dependents</th>
<th>Number of independents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Below 15 years</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>15--40 years</td>
<td></td>
<td></td>
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<tr>
<td>41-59 years</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>60 years &amp; over</td>
<td></td>
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</tbody>
</table>

3. Would you indicate the number dependent and independent members of your family?

4. Has there been a change in your family size, age structure and sex composition in the last 5/10 years? If yes, please explain it.

5. Who is the breadwinner of the family?

6. Was there a deceased person in your family? If yes, please respond to the following questions:

(6.1) Who was deceased? When did the person die?
(6.2) For how long had the deceased person been sick?
(6.3) Do you know the causes of his/her death? If yes, please explain it.
(6.4) What do you think you have missed a lot due to the death of that family member?
(6.5) What problems have you and other family members encountered due to his/her death?
(6.6) What coping mechanisms have been utilized to ameliorate the problems?
III. Household Income and Expenditure

1. What are the sources of income for your family?
2. Do you get assistance in cash, in kind, or in other ways other than your income? If yes, please respond to the following questions:
3. From whom do you get assistance/support? GOs, NGOs, CBOs, religious institutions, the local community or others?
   - What kind of assistance have you received so far?
   - What are the major care and support services you are receiving?
   - Can you tell me as to how you are managing to survive with the existing situations?
4. How much do you spend for education?
5. Are you a member of any community based organization? If yes, to which you belong?
   (1) Iddir (2) Mahiber (3) Iquib (4) Debbo (5) Meredaja (6) If any, .....................
6. Who contributes a lot to the expenditure or income of your household? Why?
7. Has there been a change in income/expense of your family in the last five years? If yes, to what extent has it increased/decreased and why?
8. If you have any additional comments on the issues discussed, you may add.

IV. Responsibilities of older care givers as care providers to AIDS orphaned children

1. Is there anyone who receives care from you? If yes, how do you become a care giver and for whom do you care for?
2. What are some of your responsibilities as care providers to OVC?
3. Has HIV/AIDS resulted in a change in the roles in your family? If yes, how and to what extent?
4. Experience of care giving (how long taking care, why came/how got role)
5. What resources available (financial, and social) to provide care to OVC?
6. Do you get support from other people? If yes, from whom do you get support? What are the supports are you getting?

V. Questions to find out the challenges experienced by older care givers in the process of providing care to AIDS orphaned children and their coping mechanisms to mitigate the Challenges
1. What challenges have you encountered so far in providing care and support for
care and HIV/AIDS infected and/or affected persons in your family (economic, social, emotional
and physical)?
2. Have you ever encountered secondary stigma in the community as a result of providing
care to your grand children who lost their parents due to HIV/AIDS? If yes, how did you
experience secondary stigma? (Probes: reduction of daily interactions with family, friends and the community, loss of social networks, decreased/increased visits from
neighbors, loss of power and respect, gossip, verbal abuse)
3. What additional problems other than the problems stated above?
4. What coping mechanisms have you used so far to mitigate your problems
5. How do you assess the attentions of the government, NGOs, CBOs, religious institutions
and other stakeholders given to older people as compared to other Segment of the population?

VI. Questions to find out resources available for elderly caregivers in the study area that
help them to cope with the impacts of the epidemic
1. Financial support networks (family, gov’t grants, church, etc)
2. Emotional support networks (family, CBOs, church, etc)
3. Family care giving under the extended family structures
4. Care and support given by religious institutions
5. On community care and support through Iddirs, Mahibers. Iquibs, etc. Government/non-
governmental agencies care and support systems, and others if any.

● If you have any comments regarding the welfare of elderly in general and older care
givers in particular (on policy issues, programs, the existing practices, etc) , you may add.
Annex II: Questions and Discussion Guides prepared for Concerned Governmental and Nongovernmental Agencies

**Direction:** For each of the following questions, you are requested to provide precise and true response. It is your right to refuse or discontinue from participating in this study. Finally, I would like to assure you that all your responses will be kept confidential and used only for the purpose of this study.

**II. Background information:**

1. Name of the organization/ association..................Location........Year of establishment........?
2. Why did the organization get established? The mission, vision and objectives of its establishment.
3. May you tell me the historical development of the organization/ association?
4. What are your organizations’ areas of focus? Why?
5. Who are the target groups of your organization? And why?
6. How did your organization select target beneficiaries/ clients? Indicate the selection criteria being used.
7. May you indicate the population size, age structure and poverty situation of the older caregivers?
8. What are the major strategies and intervention modalities of your organization to address the problems of elderly?
9. What are the services provided by your organization?
   (9.1) Preventive activities (9.2) Rehabilitative services (9.3) Development-oriented ones
10. Is there referral service of clients in your organization? If yes, please explain how and with whom?

**III. Issues related to the living condition of Older Caregivers**

1. What categories of older people exist in Addis Ababa, specifically in Kolfe Keraniyo sub-city?
2. Among the existing groups of older persons, who are at high risk due to lack of basic needs; education & health services; facilities and utilities?
3. What are the urgent needs/ problems of those older care givers? Indicate in rank order.
4. What are the major problems facing older care givers? And what are the aggravating factors of these problems?

5. In your opinion, what coping mechanisms do older people are using?

6. What roles does the organization play in mitigating the problem faced by older care givers?

7. What policy support exits to mitigate the problems faced by older care givers of in Ethiopia?

8. Specify the type of policies exist for older people on the aforementioned issues.

9. Has HIV/AIDS and related deaths resulted in a reversal of roles between traditional care providers and recipients? If yes, how, to what extent, and what are the aggravating factors?

10. What intervention modalities would you suggest to ameliorate HIV/AIDS induced the problems of the elderly?

11. What roles do the following stakeholders could play to address the problems of older care givers in Addis Ababa? (Which stakeholders should play which roles?)
   - The government
   - The community
   - NGOs and CBOs
   - Religious institutions Associations
   - Institutions of higher learning
   - Others, if any........

12. What do you comment on the existing services and practices provided /undertaken by the government, NGOs, CBOs, religious institutions, the family and communities to address the problems of older persons in Addis Ababa?

13. What social work interventions would you suggest to ameliorate the impacts of HIV/AIDS on the well-being of older persons?

14. What are some of your final comments on the developmental challenges of AIDS in general and its impacts on the survival of the aged in particular?
Annex III- Discussion guides prepared for FGD participants

Direction: For each of the following questions, you are requested to discuss in a group and to provide precise and true statements. It is your right to refuse or discontinue from participating in this study. Finally, I would like to assure you that all your responses will be kept confidential and used only for the purpose of this study

1. What do you know about the causes and consequences of HIV/AIDS?
2. What are the impacts of HIV/AIDS on the elderly in general and on the older care givers in particular?
3. What are the major problems of older care givers?
4. What coping mechanisms have older people used to ameliorate their social and economic problems?
5. Which groups of older care givers are highly at risk due to the absence of basic needs; education & health services; utilities and the necessary facilities? Why?
6. What are the existing care and support services provided by the government, NGOs, CBOs, the local community, families, religious institutions and other stakeholders to the older care givers? And what should be the roles of these organizations to address the problems of older persons?
7. Which one is the major survival problem of older care givers? (Please indicate in rank ordering)
   (1) Absence of basic needs (2) Lack of income for survival (3) No access to education and health services (4) Lack of social security provision (5) If any
Annex IV: Things to be observed

Observations, as data collection tool were used to have a look at the following situations:

1. Housing conditions of some older care givers.

<table>
<thead>
<tr>
<th>Category</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
<th>Needs repair</th>
<th>None</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Bedroom</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Toilet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Kitchen</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Living room</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Floor</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>6. Wall</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>7. Ceiling</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Yard</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

2. Living arrangements of the sample cases.

   Extended [ ] Nuclear [ ]

3. Social interactions and activities of individual cases in their respective localities

4. The care and support services provided for older caregivers in the study area by government organizations, NGOs, CBOs, religious institutions or other stakeholders.

<table>
<thead>
<tr>
<th>Category</th>
<th>Quality</th>
<th>Quantity</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Good</td>
<td>Fair</td>
</tr>
<tr>
<td>Government</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NGOs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CBOs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Religious Institutions</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

   Types of Services

5. Income generating activities, which some older persons are engaged

   Type

   Items being sold

   Services being provided

And other conditions / situations, which will be deemed necessary to the study, were observed and embodied in the analysis to enrich the study.
Annex V: Document Analysis

Apart from different literatures, the following documents were reviewed and embodied in the analysis to enrich the study.

- Different social work and other social science theories related to the topic
- Final draft of Social Protection Policy of Ethiopia
- HIV/AIDS Policy of Ethiopia
- Strategic Plan for Intensifying Multisectorial Response to HIV/AIDS
- The Standard Service delivery Guideline for Orphan and Vulnerable Children
- The Addis Ababa City social welfare strategic plans, and policy frameworks, if any.
- National Plan of Action of Older Persons of Ethiopia
- The United Nations Conventions and Declarations on Ageing, etc

Annex VI: Consent Form for Participants of the Study

My name is Zerubabel Elias. I am from School of Social Work at Addis Ababa University. I am currently collecting data for my Thesis Project entitled “An Assessment of the Living Condition of Older Caregivers to Children Orphaned due to HIV/AIDS Epidemic: the Case of Kolfe Area, Woredas 11,12 and 13 of Kolfe Kerani yo Sub-city, Addis Ababa”. As part of my assessment, I am talking to a wide cross section of people in the study area. I will use the information for the fulfillment of the thesis requirement and if necessary, the report may be submitted to concerned bodies, which would use the information to plan relevant interventions that would address problems of the older care givers who provide care to children orphaned due to HIV/AIDS epidemic.
Confidentiality and Consent

I may ask some personal questions that some people may find difficult to answer. I am not going
to talk to anyone about what you tell me. Your answers are completely confidential. Your name
will not be written on this form and will never be used in connection with any of the information
you tell me. You do not have to answer any question that you deemed unnecessary and you may
end this interview at any time you want. However, your honest answer to these questions will
help me better understand the living condition of older care givers to children orphaned due to
HIV/AIDS epidemic. I would greatly appreciate your help in responding to this study. The
interview will take about 45 minutes to an hour. Would you be willing to participate?

Signature if interviewee_______________________________

Signature of the interviewer __________________________