AN EXPLORATION OF THE CHALLENGES OF GRANDPARENTING IN HIV/AIDS

AFFECTED FAMILIES IN ZAMBIA

By

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ABSTRACT

HIV/AIDS, discovered in the early 1980s, has now become a world-wide epidemic. The most affected area is Africa, in particular sub-Saharan Africa. This exploratory research project examined the challenges facing grandmothers and focused on Zambia because with 1,291,079 orphans, Zambia has the highest proportions of orphans in the world. Evidence demonstrates that grandmothers care for approximately 43% of the 845,546 AIDS orphans. Young men and women aged between 15 and 49, despite good health and higher education, have continued to die from AIDS, leaving behind children who are cared for by their grandparents and in particular their grandmothers. The experiences of these grandmothers are not known due to a paucity of studies on the subject.

This study is a scoping review of literature on HIV/AIDS in Zambia and its impact on the family. A number of journals, books, and reports were investigated. The major themes arising from the literature were identified and discussed; they include HIV/AIDS in sub-Saharan Africa and HIV/AIDS in Zambia, impact of HIV/AIDS on households and Zambia's response to the epidemic. This research uses three perspectives: conflict theory, social capital and role conflict to guide the exploration of the social impact of HIV/AIDS on families and society. The study provided an opportunity to identify and examine the challenges facing grandmothers who care for their AIDS orphans and consequently to offer potential solutions. It also contributed to a broader understanding of the social significance of HIV/AIDS.

ACKNOWLEDGEMENTS

TABLE OF CONTENTS

ACRONYM

AIDS	Acquired Immune Deficiency Syndrome
CID	Children in Distress
CDC	Centre for Disease Control and Prevention
HIV	Human Immunodeficiency Virus
IPAA	International Plan of Action on Aging
INGOS	International Non Government Organisation
PHA	Person with HIV and AIDS
SAP	Structural Adjustment Program
SGHS	Skipped-Generation Households
STD	Sexually Transmitted Disease
SLF	Stephen Lewis Foundation
MCDSS	Ministry of Community Development and Social Services
UNAIDS	Joint United Nations Program on AIDS
UNICEF	United Nations International Children's Education Fund
UN	United Nations
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
ZDHS	Zambia Demographic Health Survey
ZHDR	Zambia Human Development Report

CHAPTER ONE-INTRODUCTION

1.1 General Overview of HIV/AIDS

According to the Joint United Nations Program Report (UNAIDS: 2008) on Acquired Immune Deficiency Syndrome (AIDS), there were about thirty three million people living with Human Immunodeficiency Virus (HIV) at the end of 2007. It is estimated that by the end of the same year, the epidemic had left behind fifteen million orphans worldwide. The African continent, in particular sub-Saharan Africa, has been hardest hit by the pandemic, as the region is home to an estimated twenty-two-million people who are HIV positive. Although the region has just over 10% of the world's population, it is home to 67% of all the people living with HIV (Piot, 2008). Former United Nations (UN) Secretary General Kofi Anan notes that "the death toll from the epidemic is expected to have a severe impact on many economies in Africa, and between 1999 and 2000 more people died of AIDS in Africa than all the wars on the continent" (Shah, 2008: 2).

While a significant body of medical research has focused on the physical and mental toll which HIV/AIDS has had on individuals infected with the disease, and epidemiologists and social scientists have studied the social impact of this disease, few studies have examined experiences of specific groups such as grandmothers. It is important to recognise that AIDS has adversely affected nations, communities, and households. As young men and women between the ages of 15 and 49 represent the group most likely to succumb to AIDS, their child care responsibilities are often transferred to grandparents who are ill prepared for their new role. This study explores the challenges encountered by grandparents, in particular grandmothers, because they care for about 43% of the 845,546 AIDS orphans in Zambia. The research focused on

Zambia because with a total of 1,291,079 orphans it has the highest proportion of orphaned children in the world (Piot, 2008).

In Zambia, the first case of AIDS was reported in 1984 (AVERT, 2009). Initially, there was no political will to tackle the problem. In fact, in the early stage of the epidemic much of what was known about HIV prevalence was kept secret by government authorities under President Kaunda. Senior politicians were reluctant to speak and be associated with the epidemic because of the stigma associated with it. However, a notable exception happened in 1987 when the president announced at a press conference that his son had died from AIDS (AVERT, 2009). Following the Presidential announcement, in order to reduce HIV prevalence and incidence rates, a variety of interventions, including promotion of safe sexual behaviour, blood screening and control of sexually transmitted infections (STIs) were implemented. In 1992 a condom social marketing program was also introduced. In addition, in 2004 President Mwanawasa of Zambia declared HIV/AIDS a national emergency. To this end, a comprehensive approach was initiated to address the epidemic, which has devastated many families in Zambia, across most demographic sectors (Piot, 2008).

This study explores the resources available to grandparents who are caring for AIDS orphans. Although many studies have investigated the origins, trends, scope and devastating effects of HIV/AIDS in Zambia, there remains a dearth of studies on how grandparents are affected. The main goal of this research is to contribute to a better understanding of the social impact, as well as the scale of challenges faced by grandparents in HIV/AIDS affected families by addressing the following research questions:

1.2 The Research Questions

       1. What are the experiences of grandparents as caregivers in HIV/AIDS afflicted families?

       2. How do they cope with their new responsibilities as caregivers?

       In addressing these research questions, the objectives of the study are to:

1.3 Research Objectives

       1. Identify and analyse the needs and challenges experienced by grandparents taking care of their AIDS orphaned grandchildren; and

       2. Analyse current formal and informal institutional responses to the challenges identified. Formal institutional responses consist of support provided by government through welfare programs, while informal responses include support provided by the extended family system, such as home based care and financial assistance. By documenting the experiences of grandparents, and their challenges, as well as by disseminating key findings to stakeholders, this research has the potential to enhance measures for mitigating the situation.

1.4 Definition of HIV/AIDS

       The Human Immunodeficiency virus (HIV) causes Acquired Immunodeficiency Syndrome (AIDS). It is important to note that AIDS is not a disease, but the weakening of the immune system that is caused by HIV (Chulu, 2007). When a person has AIDS, the defence mechanism of his or her body is compromised, making it vulnerable to, and unable to recover from, opportunistic diseases (Evans & Becker 2009). HIV/AIDS is thus linked to other diseases because as it weakens the immune system, opportunistic infections find it easy to attack the body. This, therefore, means that HIV escalates the incidence of other diseases such as malaria,

tuberculosis, and diarrhoea which may lead to death. In Zambia, about 60% of tuberculosis cases are related to HIV infections (Chulu, 2007).

The main method of HIV/AIDS transmission in Zambia is through heterosexual intercourse, followed by pregnant women passing it to their unborn children, during delivery or breastfeeding, as well as through infected blood, and unsafe injections. The rates of HIV infections are highest among women due to socioeconomic problems, social norms, biological reasons, social status and failure to negotiate for safer sex. Most women in Zambia depend on men for their economic survival, and are taught not to deny their husband sex. As a result, women are often not able to negotiate condom use even though they may be aware that their spouse is having sex with other women, consequently they are prone to contracting HIV as well (Chiwele, 2007).

1.5 Origins of HIV/AIDS

The origins of AIDS have not yet been conclusively identified; however, Poku (2005) claims that although HIV/AIDS was discovered in the 1980s, it is most likely that it was there before the 1950s, but it could not be detected due to lack of proper technology. In fact, when HIV was first diagnosed in the USA it was thought to be a disease of gay men; but soon after, women were also found to be HIV positive. Since AIDS was discovered it has spread at a very alarming rate and has been labelled a global epidemic (AVERT, 2008). It is now generally acknowledged that HIV originated from the simian (monkey) immunodeficiency virus, which resembles the HIV virus. However, it has not been proven where and when exactly the virus first emerged, and scientists have unanimously agreed that we may never know the exact source. It is nevertheless clear that towards the end of the 20th century the HIV infection in humans

developed into a pandemic which has adversely affected the entire human race world-wide, especially in sub-Saharan Africa (AVERT 2008).

1.6 HIV/AIDS in sub-Saharan Africa

Worldwide, more than twenty-five million people have died since AIDS was first diagnosed, leaving millions of children as orphans (Piot, 2008). As many as thirteen million children have been orphaned due to AIDS in sub-Saharan Africa. Although, governments in sub-Saharan Africa have started providing free antiretroviral treatment to lessen the toll of AIDS, only one in three people who need treatment are receiving it. As a result, in 2007 alone, an estimated 1.5 million adults and children died from AIDS in sub-Saharan Africa. AIDS has continued to cause immense human suffering on the continent and its impact will remain severe for many years to come (AVERT, 2008). While governments are struggling with the impact of the pandemic, it is grandmothers who have taken up the challenge of caring for the next generation. "They are burying their adult children and immediately stepping in to raise orphaned children. With literally no support, these women have become the cornerstones of the response to the HIV/AIDS pandemic in Africa" (Lewis, 2008: 1).

In addition, Falola and Heaton (2007) claim that the scourge that is threatening sub-Saharan Africa shows that HIV does not exist in isolation from other diseases. This is because AIDS results in the destruction of defence mechanisms which leaves the body vulnerable to other infections. Furthermore, many different illnesses such as malaria, diarrhoea, and cholera are compounded by poverty, lack of clean drinking water, as well as parasite infestation which play a role in suppressing the immune system. Taken together, these factors are having a devastating effect on the general well being of Africans and the African economy. In this sense, the epidemic can be seen as a survival issue for Africa. The end result is that there is an impending painful

death for millions of individuals; loss of parents, destruction of family units, and the epidemic also threatens to derail the continent's prospects for development.

1.7 HIV/AIDS in Zambia

It is clear that AIDS places enormous stress on the infected individuals and their entire family. Members of the family are faced with the challenge of caring for the seriously ill and with the trauma of death. They also face economic burdens associated with health care, funeral costs, and the loss of income when the breadwinner becomes ill. This situation is compounded by the stigma associated with HIV/AIDS. AIDS kills the most productive adults and not just the elderly or the weak. The loss of this productive cohort is not only a loss of life, but also a loss of their knowledge and resources expended in educating them. Perhaps, by destroying inter-generational cultural and social capital formation, HIV/AIDS is also weakening the ability of succeeding generations to maintain developmental achievements of the past. The net effect of this is the systematic erosion of the state's ability to replenish the stock and flow of vital human capital needed to sustain socio-economic development and political governance. This is the situation in which Zambia finds itself today (Fouad, 2005).

Further, the health sector has negatively been affected as medical staff exposed to HIV also fall sick and die, compounding the problems associated with limited access to health care. Like the health sector, the educational sector is equally affected. For instance, Daad Fouad, Associate Professor of Demography at the Institute of Statistical Studies and Research Cairo University conducted a secondary study entitled the "Role of Elderly people in the Era of HIV/AIDS in Africa" in 2005. The objective of this study was to highlight the need to change the role of elderly people in the African households to that of caregivers. His main sources of data were World Health Organization (WHO) reports, a United Nations Fact Sheet on HIV/AIDS,

Help Age International, and Ageing and Development Newsletter. His findings showed that in the last decade the HIV/AIDS epidemic has had devastating but under-reported impacts on the lives of older people and those who depend on them. He concluded that older people need to be counted, supported and educated in the fight against HIV/AIDS. He argues that their different needs, roles and responsibilities need to be acknowledged and included in programs and policies in addressing this global epidemic. In addition, Fouad found that in the first ten months of 1998 Zambia lost almost two thirds (1333) of its trained teachers per year to HIV/AIDS. The demographic impact of HIV/AIDS on the Zambian economy has continued to worsen. "Rising health care and funeral costs, combined with lost income and savings, are devastating families. Losses of productivity, increased absenteeism, rising insurance costs, and training costs are hurting the economies and businesses" (Fouad, 2005: 5). The agricultural sector has equally been affected, since about 60% of Zambians make their living from subsistence farming, the loss of a few workers at the crucial planting or harvesting period can reduce the harvest. In 2002, the food shortage that hit Zambia is believed to have been caused partly by AIDS which took the lives of many workers (Fouad, 2005).

HIV/AIDS is reversing many gains in life expectancy that have been achieved through continued improvements in health and education, reduction in poverty, and economic growth in Zambia. According to Chulu (2009), life expectancy at birth has fallen from 56 years in 1980 to 37 years in 2007, and households headed by females, a child or grandparents are now a common phenomenon. Nonetheless, the full impact of HIV is yet to be felt because it generally takes an adult person about seven to ten years to die from the disease and includes costs to companies and the government associated with sick leave, health benefits, and death and disability.

In the early 1990s, it was estimated that 1 in 5 adults was HIV positive; consequently, the World Health Organization (WHO) called on the government of Zambia to establish a National AIDS Council. The political leadership did not favour the idea as they felt that the government was too busy with the reconstruction of the bankrupt economy and servicing the country's foreign debt. According to Stephen Lewis (AVERT, 2008:1), the UN's special envoy for HIV/AIDS in Africa, "throughout the 1990s the government was disavowing the reality of AIDS and doing nothing to combat the problem." In addition, in 1999, the Zambian Post Newspaper wrote an editorial, "We feel [there] has been a very poor approach to the HIV/AIDS problem by our government especially cabinet ministers, including President Chiluba. A look at what the government has allocated to the AIDS/HIV fight in this year's budget clearly reveals this irresponsibility" (AVERT, 2008: 1).

It is important to note that when leadership in Zambia finally got involved in the fight against HIV/AIDS, they waged a very aggressive educational campaign. The early campaigns involved pamphlets and posters that warned people of the dangers of AIDS and unprotected sex before marriage. The media was also used to carry messages about AIDS, and children were taught in schools about the dangers of HIV as well as how to protect themselves. Furthermore, the government of Zambia scaled up its fight against HIV/AIDS through prevention and treatment programs which included HIV/AIDS awareness, condom use, preventing mother to child transmission, music, drama, group discussions, role play and the use of television, radio and the press to raise awareness. However, none of these programs are targeted at grandparents, who are caring for almost half of all the orphans in the country.

Consequently, according to Chulu (2009), the results of the Zambia Demographic Health Survey (ZDHS) of 2007 show signs of improvement as condom use increased with sales almost

doubling from 4.7 million in 1993 to 10.6 million in 2005. Further, a survey of pregnant women aged between 15 and 49 in Lusaka indicates that the incidence rate of HIV/AIDS among this group dropped from 30% in 1994 to 24% in 2004. The general incidence rate also dropped from 16% in 2002 to 14% in 2007. The government has continued to provide free antiretroviral therapy which was introduced in 2002, because most of the people in the lower class could not afford to pay for it. The delivery of the program relies on the involvement of many NGOs, churches and the community (Chulu, 2009).

In Zambia, HIV/AIDS is not primarily a disease of the underprivileged. It also involves the wealthy, as well as the educated. The rates are high in the two urban provinces of Lusaka and Copperbelt. For instance, among both women and men aged 15-49, the HIV incidence rate in these provinces is more than twice as high as in rural areas (23% and 11%, respectively). Of interest is the fact that HIV seems to have class and geographical dimensions; for instance, prevalence increases with increasing wealth from 8% among people in the lowest quintile to 21% among those in the fourth quintile. However, it is the poor who are most adversely affected by HIV/AIDS because they lack resources to enable them to cope with its impact (Chulu, 2009).

The AIDS pandemic has been compounded by the collapse of copper prices which began in the 1970s and has continued to weaken the Zambian economy. This led men to seek work away from home. The movement of miners, seasonal agricultural workers, and young men between rural and urban centres looking for employment has contributed to the spread of HIV to new areas. As a result, the consequences of AIDS have gone beyond the household and community levels as all areas of the public sector and economy have been negatively affected. Subsequently, national development has been stifled. The Zambia Business Coalition indicates

that 82% of known causes of employee deaths are due to HIV and 17% of staff recruited is to replace people who have either died or left because of AIDS related infections (AVERT, 2008).

HIV/AIDS in Zambia is costly to most households and communities because during illness, medical costs rise, work and income are disrupted, family members are drawn away from work to provide care, and in some instances children have to work to supplement household incomes. As Poku (2005) points out, after death, funerals can be expensive; furthermore, loss of an adult undermines a family's income generating abilities adding to the work burden of surviving family members, including children. These families may experience rapid transition from relative wealth to relative poverty. HIV/AIDS is, therefore, a disaster for many families who end up selling their assets to raise money to finance caregiving for a loved one, thereby moving the family into destitution. It has been found that households headed by female and elderly persons are unable to cope with the economic impact and loss of loved ones arising from HIV/AIDS (Poku, 2005).

These factors are aggravated by a lack of a comprehensive social security system. Winston Zulu, a prominent Zambian AIDS activist, points out that in Africa many people do not save for old age due to poverty and adverse economic conditions. Children are their only investment, as children are expected to eventually take care of their parents. Nevertheless, the AIDS pandemic has changed all of this as people die at about 30 years of age, leaving young children behind. Consequently, the investment in children who are supposed to look after old people is lost, leaving the additional burden of caring for grandchildren on grandmothers. The end result is a double tragedy for older people (Lewis, 2008).

In Zambia, most people rely on non-formal social security systems and schemes because the formal system is inadequate in terms of its capacity and coverage. Informal social support is

used by the majority of people, while the formal social security scheme is only available to workers who are employed in the formal sector. In 2002, Zambia's population was about 10 million people; by the end of 2009 it had reached 11 million people. Meanwhile, in 2002, the formal social security scheme covered about "450,000 employees, corresponding to more than 90% of the formal sector labour force but to only 13% of the total labour force and 5% of the total population. The remaining 95% rely on non-formal social security arrangements" (Mukuka, et al., 2002: 75).

The formal social security system protects employees and their dependents against the loss of income through retirement, disability, maternity, sickness and death. Mukuka et al. (2002: 76) indicate that "the contribution rate payment to the formal social security scheme has been 7%, consisting of 3.5% for employees and 3.5% for the employer," and by 1993, an interest rate of only between 4.5 and 5.5% was credited to the contributions of members' accounts. However, during the same period inflation increased from 33% to 200%. Consequently, most of the people who retired received, on average, a lump sum equivalent to US$10.00. Subsequently, the social security scheme suffered considerably because of paying out such unrealistic benefits. In order to address the situation the government through parliament passed the National Pension Scheme Act of 1996. This Act was intended to streamline the pension scheme and pay out prudent amounts to its members by considering inflationary fluctuations (Mukuka, 2002).

Notwithstanding the above, the new scheme has been equally ineffective due to a number of factors, such as the poor performance of the economy and limited coverage. Coverage is only available for formal wage earners whose numbers have continued to decrease due to lack of formal employment opportunities. Mukuka et al. (2002: 86) argue that the formal social security scheme has been hampered by "low levels of people's income, the absence of physical and social

infrastructure and the limited administrative and human capital which have inhibited the implantation of a strong and viable social security system that can effectively protect its members from falling into absolute poverty."

Although the government has been trying to reorganize the formal social security system, results have been slow to come. Meanwhile, because of HIV/AIDS, most retired people die before they are able to collect their pensions, which take between 3 and 6 years before benefits can be collected. It is important to note that very few women enter the waged labour market; this, therefore, means that almost all grandmothers do not qualify for formal social security and this situation hinders their ability to financially support their orphaned grandchildren. As a result they depend on informal social support systems including their children, who are supposed to take care of them, but who are dying prematurely from AIDS. However, even grandmothers who retire after employment are often unable to provide for their grandchildren and themselves due to poor pension payments.

The work that women, especially grandmothers perform as homemakers as well as heads of households is unrecognised by society and does not attract any rewards; yet their contribution to the welfare of their families is essential to their survival. The conflict perspective as postulated by Frederich Engels (1884 in Kendall, Murray, and Linden, 2007), supports this view and shows us that many of the challenges that women (grandmothers) face can be attributed to the exploitation in their work place and in particular at home.

The non-formal social security scheme is composed of the extended family, as well as other kinship ties. The extended family provides social security needs mostly in rural areas. It takes care of births, initiations, marriage, famine, sickness, old age and deaths, and it works on the principle of reciprocal aid among members, as well as rights and responsibilities. Kayongo-

Male et al. (1984: 63, cited in Mukuka, 2002: 89) claim that the "extended family is a noble characteristic of African society especially at time of death, during disputes and in production and up-bringing of children...At times of death, the children of the deceased were looked after by extended family...The children brought into the household of relatives were treated equally with those of that household." Unfortunately, the extended family is not able to continue with this responsibility due to a number of factors including HIV/AIDS and lack of resources.

It is important to note that 60% of the Zambian population lives in rural areas which have been devastated by years of drought, along with economically and environmentally unstable agricultural policies and practices. These factors, coupled with social and economic pressures, including structural adjustment programs (SAP), rural-urban migration, poverty and HIV/AIDS, have weakened the extended family to a level that it has lost its ability to perform traditional responsibilities. It is important to recognise that the Structural Adjustment Program (SAP) was imposed on Zambia by the World Bank and International Monetary Fund as a condition for granting the country loans. SAP comprised conditions which Zambia had to implement as a way to resuscitate the economy, including, the sale of public sector corporations, the imposition of cost sharing user fees imposed on health and education, and the reduction of employment levels in the public service, mostly in the social sectors. As a result, many people lost their jobs, and this situation increased the levels of poverty in the country

Zambia is one of the poorest countries in the world. It has never had a safety net to help older adults, particularly with the provision of social security in later life. In 2006, 64% of its population was living on less than a dollar per day. However, in 2003 the Ministry of Community Development and Social Services (MCDSS) began piloting different types of cash transfer models to find out which would be suitable for the whole nation. The aim of this

program is to reduce starvation and extreme poverty among the poor, especially older adults. Pilot schemes are being run in five districts of Chipata, Katete, Kazungula, Kalomo and Monze. The "Katete program is the newest of these schemes as it was started in 2007, and differs from the other pilots in that it uses age based targeting to selected individuals instead of attempting to identify the poorest households in the community" (Knox, 2009: 2).

In this scheme, older adults aged 60 and over are given sixty thousand kwacha (K60, 000:00) per month, which is equivalent to US $11, yet the average cost of living per month for an individual is two hundred and forty thousand Kwacha (K240.00), which is approximately forty four US dollars (US$44). Although this is a pilot program, the amounts that are being given are inadequate by all standards. In fact, the scheme only covers half of Katete district, and reaches over 4,500 people, of whom 37% are women while the remaining 63% are men. This program is still experimental and as such many older adults, especially grandmothers caring for HIV/AIDS orphans, are yet to be included (Knox, 2009). So far the progress of this program has not been reported in the literature.

The next chapter outlines the theoretical framework used to guide this research including: conflict theory, social capital, and role conflict, and indicates the reasons why these perspectives were selected and how they were combined.

CHAPTER TWO- THEORETICAL FRAMEWORK

2.1 Conflict Theory

This research is guided primarily by conflict theory and is supplemented by other conceptual frameworks including social capital and role conflict. Tepperman (2004: 659) claims that conflict theory is "a theoretical perspective that emphasizes conflict and change as the regular and permanent feature of society, because society is made up of various groups that wield varying amounts of power." Conflict theory shows us that social structures in society promote inequality as the rich and educated tend to be placed at the top, while the poor and uneducated are placed at the bottom. Women, typically older women, tend to be poor and at the bottom of the social hierarchy. This means that in Zambia, people in the upper social class (particularly men) tend to be healthier than those in the lower social classes because they have the financial resources and social connections to access better health services.

It is important to note that the structure of health services in any society encourages, maintains, and reproduces social class structure and social hierarchies. In this case, the way that medical services are organised perpetuates class inequalities. In Zambia the health system is controlled by both the private and public sectors. First, the private sector manages institutions that are skewed towards a profit motive. For instance, St. Johns and Care for Family Business Hospitals in Lusaka charge high prices for their health services. Second, the public sector manages institutions that are service oriented such as provincial general hospitals and the University Teaching Hospital (UTH) in Lusaka. Private sector health institutions are well equipped with the latest machinery, drugs, and a highly motivated workforce which has better conditions for providing service. Public institutions, because they are funded by the government, tend to lack necessary equipment, drugs, and have a de-motivated labour force due to the large

volume of patients with pressing problems. Private health institutions are a preserve for the rich and upper class that have the financial resources to pay for expensive procedures and access to the top health resources in the country. Many grandmothers who are poor and responsible for their HIV positive children and their orphaned grandchildren tend to use public health institutions. These facilities may not provide antiretroviral drugs (ARVs), even if the grandmothers could pay for them, which they cannot due to costs in stocking issues and accessing these crucial drugs. The magnitude of the access problem is alarming. According to Piot (2008), in Zambia, in 2005, out of an estimated 153,000 people who needed ARVs only 26,000 to 30,000 were receiving them. This means that most of the poor people who needed the drugs were unable to get them, resulting in a high rate of death. Figures regarding grandmothers' access are not available.

According to Karl Marx, major conflicts are situated between two classes, the bourgeois (upper class or capitalists) who own the means of production and the proletariat (lower class or workers) who are labourers. Marx argued that the competing class interests, particularly in regard to the modes of production are the primary basis of conflict. It is important to recognise that the upper classes have more resources, power, and prestige which are used to maintain their position of power and to exploit and oppress the lower classes. Consequently, social inequality is maintained over long periods of time. As the proletariat strives to move upwards on the social stratification ladder, the bourgeois uses every resource in its power to continue oppressing and exploiting them, resulting in a continuous power struggle between the two classes. The primary motivation of the bourgeois is to maximise profits which tends to come at the expense of the proletariat. Eventually, according to Marx, this culminates in a conflict as the proletariat defends itself. According to this perspective, change occurs as a result of conflict between classes; as the

proletariat continues to press the bourgeois for change. The struggle and injustice that result from this conflict affects all sectors of society including health, and the ability of people to access health care (Kendall et al. 2007).

This is why Friedrich Engels (1845, in Clarke, 2004) bemoaned the working conditions enforced by the capitalists in Great Britain which adversely affected the health of workers. In their attempt to maximise profits, capitalists reduced the cost of labour and as a consequence workers could not afford food and decent housing. Instead, they lived in slums without clean water and sanitation. As a result, their health was poor due to diseases from poor living conditions. Engels further claims that although the standard of living for workers in the world has continuously improved, inequalities and exploitation of one class by the other has continued to contribute to the escalation of diseases such as malaria and tuberculosis. This situation is similar to the kind of life and the health problems that poor people are experiencing in Zambia today. The system of exploitations of workers in Zambia has been sustained by government failure to formulate a framework to regulate salaries and wages for workers. Consequently, a majority of the workers are underpaid. For instance, the researcher is aware of some foreign mining companies in Zambia that pay their workers equivalent to USA $200 per month, yet these companies make millions of dollars in profits. It is therefore evident that this low level of remuneration is not adequate to enable a person to sustain his family comfortably.

Conflict theorists study the social injustice associated with economic arrangements in society and how they affect people's lives in general and families in particular. The conflict perspective contends that the economic dominance of one class over others is the underlying cause of whether a group will enjoy good health or ill health. Access to adequate health services only benefits those with appropriate financial means is clear from this perspective that the

challenges facing grandparents in HIV/AIDS afflicted families in Zambia are in part due to sustained poverty and social inequality experienced by the large proletariat.

Navarro (1976) reports that contemporary capitalism has two objectives: First, the state interferes in the health sector to promote capitalist interests, by reproducing the class structure in society within the medical sector. This simply means that those who have power and resources also have access to better medical services because they can pay for their services. Second, individuals are held responsible for their illness and health is treated like any other commodity. It is therefore clear that gender and class have a bearing on whether a person will be able to access health care services. The upper classes and men in particular tend to have better access to health services because they have better financial resources than the lower classes, especially women who are less likely to pay for expensive health services.

In Zambia, grandmothers from the lower social classes have little power and extremely limited access to resources, such as financial, educational, health services, and housing, and consequently they may not be able to provide adequate care for their children and grandchildren. It also means that they are less able to provide for their basic needs including nutrition and sanitation. Navarro (1976: 209) claims that the "expropriation of political power, work and health takes place collectively and not individually." Grandmothers' lack the resources needed to create their own networks and groups to bring government attention to their plight. The current situation where grandmothers are essentially left alone to face the challenges inflicted by HIV/AIDS on their families is in line with the capitalist perspective of individualism. When individuals are responsible for their own care, the magnitude and desperation of the situation tend to be ignored by those in power.

Conflict theorists also see families as a "source of inequality and conflict over values, goals and access to resources and power and affect women in particular" (Benokraitis, 2002 in Kendall, et al. 2007: 470). Engels argues that the relationship between husband and wife is similar in many ways to that between capitalists and workers. Just like workers are exploited by capitalists, women may be exploited by their husbands and the state through the unrecognized and unpaid work they perform within their families. For example, child-rearing and housework which contribute to family well being are not financially rewarded. Similarly, the work that grandmothers of AIDS-orphaned grandchildren perform does not attract any financial or social rewards. Although there has been progress in terms of increased numbers of women entering the labour force, they are still constrained by issues of gender inequality and challenges of balancing a career and home responsibilities. As a result, the responsibilities of caring for orphaned children falls largely on them and not the grandfathers. However, it must be recognized that some of the women from the upper class are economically independent; and their situation in caring for orphaned grandchildren is markedly different.

It is important to realise that the family is necessary for socialising children. When parents die and grandparents take over the responsibility of caring for their grandchildren, the family loses the ability to perform its functions, thus adversely affecting the lives of children. Kendall, et al. (2007: 470) support this view and claim that the family is important because it is responsible for teaching children the necessary knowledge and skills to survive, providing economic and psychological support, and conferring social status, as well as maintaining the reputation of its members.

The family, as the primary focus of procreation and socialization of children, is a very important institution and establishes the foundation of life for children. Children acquire most of

their values, beliefs, norms, language, and attitudes from their parents. Families also provide love, understanding, security, and companionship for its members. However, when parents are HIV positive or prematurely die due to HIV/AIDS, children's lives and the process of socialization are disrupted. This is because sick people may not be able to fulfill their roles, such as parenting, or socializing children, and working in the paid labour force. In addition, even the loss of one parent adversely affects the life of children. For example, traditionally the husband/father fulfilled the instrumental role (i.e., meeting the family's economic needs and providing leadership), while the wife/mother fulfilled the expressive role (i.e., running the household and caring for children). Socializing of children is easier when both parents are available (Kendall, et al. 2007).

There is a significant lack of research about the role of parents in terms of the psychological impact of AIDS on the family. De Witt (2007: 4) argues that "studies on orphaned children have not yet examined the full psychological and socio-cultural impact of not being nurtured by parents." Grandparents are often not able to provide sufficient socio-emotional and educational support for orphans because they are constrained by a lack of resources and social support in orphan-hood. Grandmothers, as a result, may not be able to adequately discipline, socialize or even provide the basic needs of nutrition, clothing, shelter and health care. In other words, HIV/AIDS affected families may not be able to prepare children for entry into society as adults. Consequently, the family, children, and society at large are adversely affected when parents die from AIDS.

As grandmothers continue to struggle for survival, they have little time to establish and participate in community activities such as clubs, volunteering, entertainment or church attendance; meanwhile, the rich are busy entrenching their positions by using their connections

(social capital) with fellow privileged people and hence they continue to amass power and resources at the expense of the poor. The ability to organize is required for citizens to be able to collectively resolve the challenges associated with HIV/AIDS. For orphaned children to develop fully they need networks within their families and schools, which will enhance their educational and employment opportunities, and their behavioural development. Grandmothers' inability to organise and to bring attention to their plight works against the life chances of AIDS orphans. This contrast in the availability of social capital illustrates one of the central issues raised by conflict theory.

The conflict perspective was selected as the primary guide for this research because it provides a framework for understanding both the micro and macro relationships between social inequality in society and disparities in health. As the upper classes continue to exploit the lower classes, poor families such as those headed by children and grandmothers will go deeper into poverty and continue to experience more prevalent health problems, while they struggle to meet their basic needs and to access the health and social services required to deal with the effects of HIV/AIDS on their families. Raphael (2001: 224) agrees and contends that "materialist arguments appear especially relevant to understanding the health effects of poverty. Clearly, poor diet, housing, and sanitary conditions resulting from lack of income can contribute to poor health." This is clearly in line with the kind of life grandmothers are experiencing because they are poor.

It is necessary, however, to recognise that the conflict perspective has been criticised for not paying enough attention to social stability and shared values. For example, the family and society in general are stable because of the social structures that pattern behaviour in both the family and society. Nevertheless, a conflict perspective is still suitable for this research because

it situates what HIV/AIDS is doing to society and families within the broader structures of social inequality.

2.2 Social Capital

The second framework guiding this study is social capital, which shows the importance of social support (help that others provide) in mitigating the impact of HIV/AIDS on families and women in particular. It is important to note from the beginning that there is no consensus on the definition of social capital. Despite the lack of a clear definition, there are a few unifying themes. For example, according to Field (2003), one of the underlying assumptions of social capital is that relationships are a valuable asset. Hence, interactions are important in building communities and establishing a sense of belonging and commitment. In fact, communities with more social capital tend to have lower crime rates, better health, higher education, and a better economic growth (Smith, 2002-2009). Portes (1998) argues that Bourdieu's conception of social capital comprises two related components; social relationships as a medium to access resources, as well as the quantity, quality, and availability of resources for individual's future use. By comparison, Putnam (1994: 67) claims that social capital "refers to features of social organizations, such as networks, norms, and trust that facilitate co-ordinations and co-operations for mutual benefit...enhancing the benefits of investment in physical and human capital." Social relationships provide assistance in times of need. For instance, a person who is HIV positive needs to access resources to meet basic needs such as soap, food and money which can easily be provided by such networks. The more frequent, and the longer the interaction between people, the more likely that the relationships may become deeper and meaningful. These networks form the basis of reciprocity which is the cornerstone of social capital. The central theme of

reciprocity is that people help others without expecting anything in turn, being confident that one day when they are in need, someone will help them.

Putnam differentiates between two forms of social capital: bonding and bridging. Wuthnow (2002: 670) defines bonding social capital as "the interpersonal solidarity that is often present among people who associate in small groups, local communities, and other settings over extended periods of time." Bonding social capital is therefore a source of emotional connections between individuals in families, and close friends of the same ethnic group. However, bridging capital involves different and diverse heterogeneous social groups (Granovetter, 1982). It is important to acknowledge that bridging social capital is not as useful as bonding social capital for families that are afflicted by AIDS because it is less likely to provide emotional support.

In this thesis therefore, the definition and operationalization of social capital follows the works of Field (2003), Smith (2002-2009), and Putnam (1994), and focuses mainly on bonding social capital, especially its benefits in terms of social support. According to Reis (1996: 2), social support includes "tangible (material) assistance; information (i.e. advice and guidance); emotional support; self-esteem boosting; and group belonging." There is a link between social support and health which is based on the premise that support reduces the effects of stressful life events and promotes health because it acts as a distress buffer through supportive actions of others, such as advice or assurance. Social support may be provided by a network of family, neighbours, and community members that is available in times of need to give psychological, physical, and financial assistance. Social capital is created by institutions such as the family, school, community, and kinship networks.

Putnam emphasizes that social capital is more beneficial for group members than those on the outside. "It is exclusive or inward looking and tends to reinforce exclusive identities and

homogeneous groups" (Putnam, 2000: 22). It is clear that grandmothers as caregivers can only benefit from social capital if they are a part of a recognized group. It is apparent, therefore, that participation and investment are keys to being able to reap the benefits of social capital. It is obviously not possible for grandmothers who are preoccupied with survival to invest and participate in communities where they live. It is also difficult for those with limited financial resources to organize effectively into groups to provide social support.

According to Putnam (2000) people connect formally through political parties, civic associations, churches, and unions. They also connect informally by going out for a drink, playing games, sharing a meal, gossiping with the next door neighbour, even simply nodding to someone as they pass by. All these encounters are expressions of social capital. As grandmothers continue to struggle for survival, they have little time to establish and participate in community activities such as clubs, volunteering, entertainment or church attendance; meanwhile, the rich are busy entrenching their positions by using their connections (social capital) with fellow privileged people and hence they continue to amass power and resources at the expense of the poor. Since grandmothers lack the financial and social support to organize, they are more likely to be ignored by those in power.

Strong social capital is required for citizens to be able to collectively resolve the challenges associated with HIV/AIDS. For orphaned children to develop fully, they need networks within their families and schools which enhance their educational and employment opportunities as well as their behavioural development. A lack of social capital negatively affects the life chances of AIDS orphans. Grandmothers as caregivers face tremendous psychological and financial pressures and therefore have no opportunity to establish and strengthen their social capital. Putnam (2000: 192) supports this view and argues that "it is true that financial worries

and economic troubles have a profoundly depressing effect on social involvement, both formal and informal."

The importance of social capital stems from the fact that, poor or rich, every individual, community and nation cannot do without it. Social capital enables citizens to resolve challenges collectively, widens people's knowledge about how their fates are linked, and is the glue that cements relationships. Also, evidence demonstrates that people who are rich in social capital cope better with traumas and fight illness more effectively. Social capital is therefore a complement to drugs when one is sick (Putnam, 2000).

Further, Putnam (2000) contends that social cohesion enhances good health because social networks furnish tangible assistance, like money and care, which reduces stress and provides a safety net. Social networks may also reinforce healthy habits, as socially isolated people are more likely to smoke, drink, overeat, and be involved in health damaging behaviours. Also, social capital may stimulate people's immune systems to fight disease and buffer stress.

There is no doubt that social relationships and affiliations enhance physical and mental well being. Studies have concluded that the more social support an individual receives the better one's health. According to these studies, social support may promote disease resistance by strengthening the immune system and enhancing self-esteem. For instance, in their study in Alameda County in California, Berkham, & Syme (1979: 1) found that "men and women who lacked ties to others were 1.9 to 3.1 times more likely to die than those who had many contacts." In Sweden, the Goteborg study showed that "in different cohorts of men, social isolation proved to be a risk factor for dying, independent of biomedical risk factors" (Welin, 1985: 1, in Berkham, 2002). From the above examples, it is clear that social support is necessary not only for good health but it also helps people to recover from various kinds of diseases and distress. In

contrast, lack of sound social relationships tends to have a negative effect on an individual by causing anxiety and despair, as well as poor physical and mental health. Grandmothers and their orphaned grandchildren may lack social capital and may not be able to benefit from social support due to the stigma that is associated with AIDS. It then follows that their physical and mental health would suffer.

Social capital is second to poverty in influencing children's lives. "Research dating back at least fifty years has demonstrated that trust, networks, and norms of reciprocity within a child's family, school, peer group, and larger community have wide-ranging effects on the child's opportunities and choices and, hence, of his behaviour and development" (Putnam, 2000: 296). Social capital is so important that it helps to keep teenagers from dropping out of school, hanging out on the streets and having babies out of wedlock. Social capital, at the community as well as family levels has a positive effect on children's birth weight and eventual development (Putnam, 2000).Therefore, using this logic, street children in Zambia are more likely not to perform well in school due to lack of social capital; consequently, their future may be bleak.

In summary, a lack of sound social relationships tends to have a negative effect on an individual by causing anxiety and despair, poor physical and mental health. Grandmothers and their orphaned grandchildren lack social support due to the stigma that is associated with AIDS. It then follows that their physical and mental health would suffer making them prone to anxiety and despair. There is therefore a clear positive relationship between social support and good health.

The limitations of social capital are well documented, as Wilkinson (2003: 4) argues that "these competing definitions make it difficult to utilize social capital in a meaningful manner. If we lack consensus as to the precise definition, then how can we measure this concept and be

assured of its reliability and validity?" Even though there is little consensus about the definition of social capital, there is an awareness of its importance as evidence demonstrates that support from others can protect people from various challenges in life including depression, alcoholism, distress, and social breakdown (Reis, 1996). As a result, people who are affected and infected with HIV/AIDS need social support which is facilitated by social capital in order to lessen the burden of the disease on their life and this is why social capital is being used in this study.

In addition, although social capital is an important perspective, Smith (2000-2009) argues that it should not be taken for granted because it has weaknesses. First, he claims that it is not yet fully developed as a theory. Second, it has failed to properly address the gender dimension of social capital, and third, much of the discussion of social capital has treated it as a positive attribute, yet some people are able to access resources and power at the expense of others (Smith, 2000-2009). However, social capital is still appropriate in guiding this research because it highlights how important social support is in mitigating pressures of life. According to this model, grandmothers and their orphaned grandchildren are unable to surmount the challenges they encounter at home and in the community because they lack social capital.

2.3 Role Conflict

The third conceptual framework guiding this research is role conflict, which helps us understand how HIV/AIDS has caused changes in the status and roles of grandmothers. The advent of HIV/AIDS has resulted in role conflict and its off-shoot of "role overload (which occurs when one perceives that the collective demands of multiple roles exceed available time and energy resources, thereby making an individual unable to fulfill adequately the requirements of various roles)" and "role strain (which occur when the strain of one role spills over into another role)" (Turner, 2002: 848). Role strain simply means trying to meet the expectations of

too many different roles, while role overload is dealing with the competing demands associated with different roles.

As indicated earlier, it is evident that HIV/AIDS has caused changes in the status and roles of grandmothers which have resulted in role conflict. Roles are patterns of behaviour that are associated with particular positions in a social structure, and reflect the normative behavioural expectations related to our social status in society (Park, 1926 in *The Black Dictionary of Modern Social Thought,* 2002). Merton (1949) and Goode (1960) in The *Black Dictionary of Modern Social Thought,* (2002) argue that many people play various roles and face challenges, especially role strain and role overload. In addition, this conceptual framework contends that individuals may be compelled into deviant roles due to structural roadblocks preventing them from satisfying their cultural ideals. It is evident from this perspective that orphans who have no resources are compelled to indulge in prostitution and crime. Consequently, an individual's inability to meet these challenges may lead to anger, fear, sadness, shame, and poor quality of life, while success results in happiness, pride, and satisfaction.

This clearly applies to grandmothers and children who are heads of households that are affected by HIV/AIDS. Grandmothers experience role strain and role overload because of marital inequality with their spouse (if they have one), exclusive parenting responsibilities, unclear expectations and a lack of emotional and social support. This family structure means that grandmothers function as primary caregivers looking after their own children who may be suffering from HIV, and helping their grandchildren with homework and teaching them cultural norms and values. As head of the family, a grandmother is also expected to work outside the home and earn resources in order to be able to provide for the needs of family members. In sum, it is not difficult to understand why role overload occurs.

Undoubtedly, it is extremely difficult to fulfill these roles without any social support. Consequently, grandmothers' increased family responsibilities lead to role overload and role strain. This situation has far reaching consequences for grandmothers, linked to poor physical, mental health, stress-related outcomes, including anxiety, fatigue, burnout, and decreased satisfaction with family life. For example, as Burnett (1999 in Fuller-Thomson, 2005: 339) confirms, "grandmother caregivers were overloaded with too many role demands and inadequate resources to meet those demands, which in turn undermine their self-esteem." In addition, Fuller-Thomson in his study in 2005 found that in comparison to non-caregiver grandparents, grandparents raising their grandchildren experience more depressive symptoms, higher levels of poverty, role overload and role strain. Children heading households experience similar challenges. However, in Zambia, the effect of role overload and role strain on grandmothers and children heading households is not known due to a paucity of studies on the subject.

Role conflict has limitations, as Hartley (1999) argues stemming, for example, from the fact that roles themselves have always been highly fluid and are rarely rigidly defined. He claims that it may be inappropriate to attribute conflict to roles because there may be other prominent factors affecting conflict, including ego, temperament, and bias. Nevertheless, role conflict has been used because it provides a basis for analysing and interpreting challenges encountered by grandmother caregivers at the micro level in their daily social relationships.

2.4 Integrating the Theoretical Frameworks

The three theoretical perspectives used in this research offer a comprehensive basis for understanding why grandmothers have been impacted negatively by HIV/AIDS. These perspectives made it possible to explore the macro and micro levels of analysis, as well as the structural and behavioural dimensions of the research questions. The perspectives also outline

the social consequences of the epidemic for the lives of grandmothers and provide a basis for formulating solutions to ameliorate the challenges they encounter.

It is clear from conflict theory that grandmothers are facing these challenges because they are members of a vulnerable group which has little power or resources, and therefore, little to no influence. Role conflict shows us that these challenges result in role overload and role strain for grandmothers. In addition, social capital helps to conceptually link the social environment in which grandmothers live and provide care (i.e. the structured inequality in Zambian society highlighted by conflict theory) and the behavioural dimensions of the HIV/AIDS epidemic illustrated by the role conflict perspective. Finally, social capital brings to our attention the fact that with enough social support grandmothers would be better able to surmount some of the structural and personal problems they are facing.

CHAPTER THREE-METHODOLOGY

This research is a scoping review of existing literature. A scoping study is a type of literature review that enables researchers to note any gaps in the literature on a particular subject, summarise, and report their findings. There is, however, no clear definition of a scoping study. According to Mays, Roberts, & Popay (2001: 194 in Arksey & O'Malley, 2005), "at a general level, scoping studies might aim to map rapidly the key concepts underpinning a research area and the main sources and types of evidence available, and can be undertaken as stand-alone projects in their own right, especially where an area is complex or has not been reviewed comprehensively before." This scoping study discusses the challenges faced by grandparents in HIV/AIDS afflicted families in Zambia and the formal and informal response to these challenges. A scoping study is appropriate because this research is a literature review to map relevant findings on the social impact of HIV/AIDS. This scoping study examines broader dimensions of the needs and challenges experienced by grandparents taking care of their AIDS orphaned grandchildren (Arksey and O'Malley 2005).

The purpose of utilizing a scoping review in this study was to identify comprehensive information that would be appropriate for addressing the research questions and objectives. A scoping study was suitable because it enabled the researcher to identify and analyse the challenges experienced by grandmothers caring for AIDS orphans. It also facilitated an analysis of the role played by formal and informal sources of support in mitigating the impact of the epidemic on the family and society in general. However, since this scoping study uses secondary data, there are still gaps which require primary research to be adequately addressed.

3.1. Data Sources

A scoping study uses secondary data; therefore, research papers and reports published between 1984 and 2009 were reviewed. The start date for this research (1984) was chosen because this was the time when the first case of HIV was reported in Zambia. Several electronic online bibliographic databases such as Ageline, Scopus, Medline, Sociological Abstracts, and JSTOR were used. The UNAIDS/WHO global HIV/AIDS Online Data Base and the AIDS Public Use Data (CDC Wonder Data Base) were also utilized. Scholarly papers focusing on grandparenting and HIV/AIDS, reports and policy documents from the government of the Republic of Zambia and Non-Governmental Organizations (NGOs) were searched. In order to retrieve information from electronic search engines the following key terms were used to conduct the search, independent of each other: HIV/AIDS in sub-Saharan Africa, HIV/AIDS in Zambia, grandparenting and HIV/AIDS, orphans and HIV/AIDS, as well as grandmothers and HIV/AIDS.

3.2 Data Collection Procedures

Key concepts derived from the research questions were used to search for both electronic data and books. Over one hundred journal articles and abstracts were retrieved and reviewed, but only 62 that contained relevant information were used. Four reports on HIV/AIDS compiled by the UN were used. A total of thirteen books on HIV/AIDS and three reports from the government of Zambia were the other sources of literature. Half the journal articles reported the results of epidemiological research and the other half were gerontology studies. Almost eighty five percent of the sources were qualitative studies, while about fifteen percent were quantitative studies. Journals such as *the Gerontology Society of America and Reproductive Health Matters, the Journal of HIV/AIDS and Social Services, the Journal of Clinical Epidemiology, and the*

Journal of Child and Adolescent Mental Health, and International Journal-Aging and Development were the main sources of data

The material was sorted and summarised, and the findings are presented in terms of the major themes identified. The themes that came to the fore from the literature review include the impact of AIDS on sub-Saharan Africa and the impact of AIDS in Zambia, in particular on households, children and grandmothers, the response of the government of Zambia to the epidemic and the significant role that grandmothers are playing to address the impact of AIDS on the family. Other major themes that were derived from the literature review include stigmatisation of HIV/AIDS, experiences of HIV/AIDS afflicted families, and their coping strategies. The major themes were electronically searched on the Internet and websites such as the University of Manitoba, the United Nations, and the Stephen Lewis Foundation, and copies of journal articles and reports were printed. In addition, books were collected from the Elizabeth Dafoe Library at the University of Manitoba. The resources that were not available in the Dafoe Library were obtained from the Neil John Maclean Health Sciences Library and the Carolyn Sifton-Helene Fuld Library at St. Boniface Hospital.

These are the major sources of data that were available to this researcher for addressing the stated research questions. The resources were adequate to provide a realistic assessment of the central objectives of the study. For instance, research papers by scholars such as by Baranyai (2000) provided information on full time grandparent caregivers, their feelings and experiences and how HIV/AIDS has affected families and grandmothers in particular. Baranyai's paper explored the experiences of grandparents caring for their grandchildren in 2000 in Toronto. This paper helped to confirm that the challenges of grandparenting are universal and that the role of grandparents has altered to include full time parenting again. Another paper entitled

"Grandmothers Called Out of Retirement: The Challenges of African Women Facing AIDS Today" written by Wane and Kavuma (2001) highlighted the fact that the extended family has been broken-down by HIV/AIDS and lacks the capacity to pass on knowledge to the younger generation

Further, Chiwele, Luo, Kapungwe, Sireh-Jallow, Chirwa, Virmasalo, & Kumwenda, (2007), provide additional material; they state in the Zambia Human Development Report (ZHDR) of 2007 that the extended family system is under severe stress and is failing to cope with the impact of HIV/AIDS. Consequently, in 2002, the Zambian parliament passed the National HIV and AIDS Bill that empowered the National HIV/AIDS/STD/TB Council (NAC) to organize and coordinate programs and activities in the country to respond to the crisis. This report documents the adverse effects that HIV/AIDS has had on the country and families in particular. It shows concerted efforts of the government and its partners (the UN, President Emergency Plan for AIDS relief by the US, the donor community, NGOs and faith based organizations) to handle the epidemic (Chiwele et al., 2007). "The report also shows that HIV and AIDS reinforce poverty while poverty in turn makes people susceptible to HIV and AIDS" (Chiwele et al., 2007:10).

In additional, published reports by the United Nations International Children's' Education Fund (UNICEF), United Nations Joint Program on AIDS (UNAIDS) and the Stephen Lewis Foundation (SLF) supplemented the above sources. These sources were selected because they contain the most recent, accurate and significant materials on HIV/AIDS. The UNICEF and USAID compile statistical information on the prevalence rate of HIV/AIDS worldwide and in Zambia in particular.

Further, the Joint United Nations Program on AIDS (UNAIDS) report of 2008 provided information such as the status of the global HIV epidemic in sub-Saharan Africa from 1990-2007 as well as highlighted the measures that the UN in collaboration with its member states have implemented to mitigate the epidemic's impact on households, communities and societies. The report states that progress has been made in combating the epidemic as evidenced by the falling infection levels around the world. However, Piot (2008), cautions that much more needs to be done in order to combat the epidemic since for every two people who are put on antiretroviral drugs, another five get infected.

Meanwhile, the Stephen Lewis Foundation (SLF) provided additional information on its activities in Africa, and Zambia in particular. These reports include topics such as the history, prevalence rate, and impact of HIV/AIDS on the family, as well as the intervention measures that the government has put in place. The SLF is the only organization that has programs targeted at alleviating the challenges that grandmothers are facing because of HIV/AIDS. For instance, in 2004, the SLF financed a grandmothers' project in Kabwe, Zambia, called Busy Bees. This group comprises grandmothers who are infected or affected by HIV/AIDS and most of whom are caring for HIV/AIDS orphans (Lewis, 2006-2007).

3.3 Data Analysis Strategy

A latent strategy was used to sort and code the data. The analysis for this research involved identifying the major themes that arose from the literature review such as HIV/AIDS in sub-Saharan Africa, impact of HIV/AIDS in Zambia, impact of HIV/AIDS on the economy, impact of HIV/AIDS on households, challenges faced by grandmothers, and Zambia's response to the HIV/AIDS epidemic. All the data was sorted into these themes which have been used to guide the interpretation of findings and to organize the subsequent discussion of the challenges

faced by grandmothers as caregivers for AIDS orphans. The experiences and quality of life of grandmothers and their AIDS orphaned grandchildren were extrapolated from the literature reviewed. These experiences enable us to understand the impact that HIV/AIDS has had on the family and the nation at large. Since the conflict perspective is a theory of change, it helped to guide this study's investigation of the changes that HIV/AIDS has brought to the family and Zambian society. It has also shown the devastating impact that HIV/AIDS has had on the family and society in general due to a lack of formal and non-formal support to tackle the epidemic.

CHAPTER FOUR – FINDINGS: ASSESSING THE IMPACT OF HIV/AIDS

This chapter provides an overview of the findings of this research project. It highlights the devastating effect of HIV/AIDS in sub-Saharan Africa and in Zambia in particular. It shows that the epidemic has affected all sectors of the country including the economy, agriculture, health, education, households, and especially grandmothers.

4.1 HIV/AIDS in sub-Saharan Africa

Since the outbreak of the epidemic, more than fifteen million people in Africa have died from AIDS. Sub-Saharan Africa is the worst affected region in the world where AIDS has continued to devastate communities and entire families. About 22.4 million people, equivalent to two thirds of the world-wide total of HIV positive people, live in the region. The world map below shows that sub-Saharan Africa has the highest prevalence rate in the world of between 15% and 28% (UNAIDS/WHO 2008).

Figure no. 1   A Global View of HIV Infection (33-36 million people)-2007
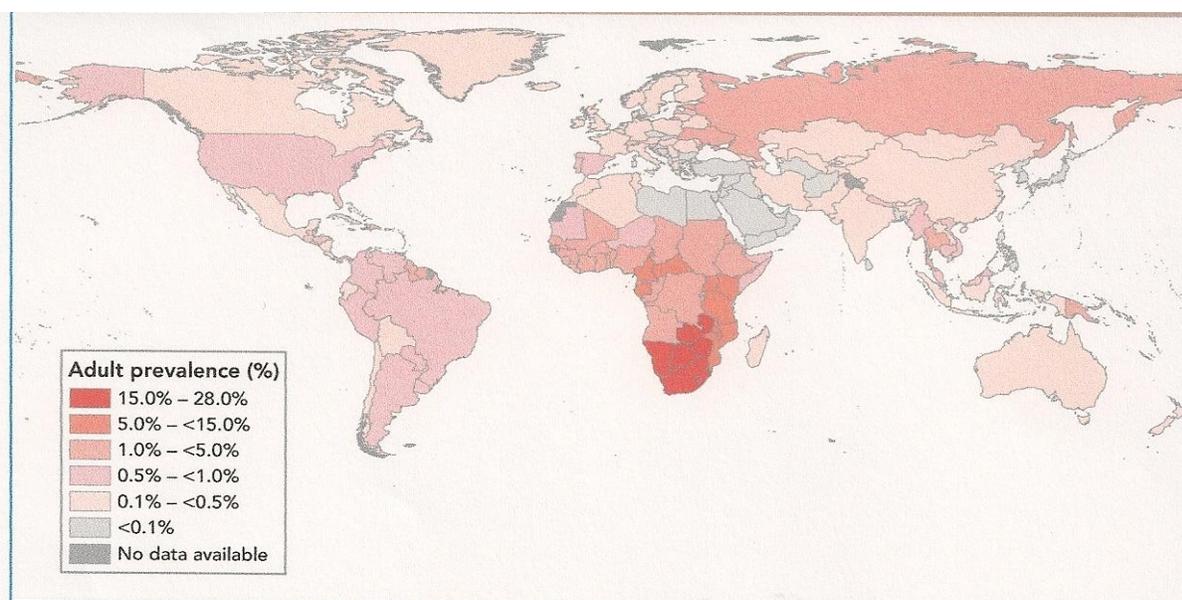
(UNAIDS/WHO, 2008: 33)

In sub-Saharan Africa AIDS is erasing decades of progress in extending life expectancy due to economic and health achievements. In most countries in the region, life expectancy has fallen by 20 years because of the epidemic. For example, in Swaziland life expectancy is 31 years, while in Zambia it is 37 years. The situation is similar to most parts of Africa where the impact of AIDS has been greatly felt (AVERT, 2009). However, many countries in sub-Saharan Africa do not have policies and programs to support AIDS orphans and vulnerable children and their grandmothers despite the rapidly growing challenges that HIV/AIDS has created in their respective countries. For instance, there is no country in sub-Saharan Africa that has specific programs/policies that are targeted at grandmothers and their orphaned grandchildren. Thus, the needs and challenges of these children and their caregivers are not well understood. For example, there is a lack of understanding of the extent to which these children are the objects of discrimination. Because grandmothers and their orphaned grandchildren lack social capital they are less able to organize coalitions to complain to governments, community organizations and the larger society about their plight. As a result, their voices are silenced in the dominant social discourse.

About 15% of children in 11countries in sub-Sahara Africa are orphans. This means that all these children, without the guidance of their parents, will have challenges to acquire knowledge, beliefs, language, religion and values of society. The AIDS epidemic is tearing Africa apart, as it throws millions of households/families into turmoil, wiping out the middle generation, and leaving children and the elderly to fend for themselves (De Witt, 2007).

Children who lose one parent due to AIDS are most likely to become double orphans in a short time because there is a high probability that the other parent is also HIV positive. In 2005, out of the 9.1 million orphans in sub-Saharan Africa, about 5.2 million had lost at least one

parent to AIDS (UNICEF, 2006). The number of orphans will continue to rise even when HIV prevalence stabilises or indeed begins to decline because of the time lag between infection and death.

Table 1 shows that children have continued to be adversely affected by HIV/AIDS. The table shows that from 1990 to 2007 the number of orphans in sub-Saharan Africa increased from five hundred thousand (500,000) to about twelve million (12,000,000). All the orphans are below eighteen years of age, and half of them have lost at least one parent due to HIV/AIDS. Equally important, world-wide, the number of children that are being infected with HIV has also continued to increase. For instance, from 2001 to 2007, the number of HIV positive children rose from one million six hundred thousand (1.6 million) to two million (2 million), and in the same year, in Zambia, about 370,000 children were infected (Piot 2008).

Table 1
Estimated Number of Children under 18 Orphaned by AIDS in sub-Saharan Africa-(1990-2007)

Source: UNAIDS/WHO, 2008.
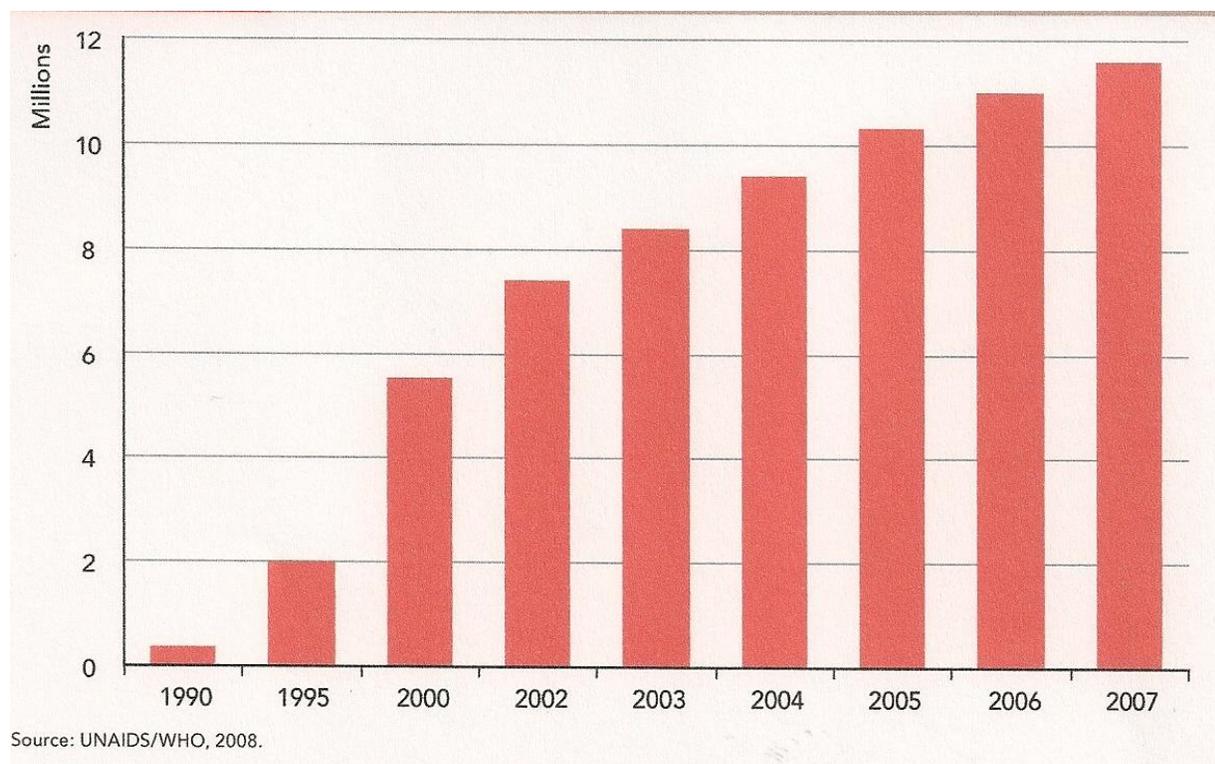
(UNAIDS 2008:163)

Research conducted by UNICEF (2006) in ten sub-Saharan African countries found that orphans living with their grandparents were doing much better in school than those living with other relatives. Since in most cases grandparents are already involved in the lives of their grandchildren, they are expected to take over the full responsibilities of looking after orphans. However, the major challenge they face is a lack of resources coupled with the fact that due to their age grandparents may not live to see their grandchildren reach the age of 18. The other problem that orphans face is that they are separated from their siblings. In Zambia, research shows that "separation of siblings was a significant determinant of emotional distress for orphans, 30% of orphans were found to be living apart from their siblings under the age of 18" (UNICEF 2006: 16). A lack of resources is therefore a definite recipe for grandmothers and their orphaned grandchildren to lead a life full of challenges.

In addition, in sub-Saharan Africa, "research conducted between 1990 and 1999 found that the mortality rate for under five years attributed to AIDS increased from 2% in 1990 to 77% by 1999; this includes only the direct impact of HIV on child survival" (UNAIDS, 2006: 19). In much of sub-Sahara Africa, there are no records indicating the exact number of children in residential institutions apart from Liberia and Zambia, which have 7500 and 5000 respectively. However, the report shows that there has been an increase in residential facilities in recent years. For instance, a study in Zimbabwe found that between 1994 and 2004, 24 new residential institutions for orphans were built. According to this report, a study in sub-Sahara Africa shows that it is better for children to be cared for and grow up in a family environment and that institutional care should only be a last resort. The report also enumerates the following as the major weaknesses of institutional care for orphans:

*High staff turnover rates that make it difficult to sustain a caring environment.

*High child to staff ratios that exacerbate the care deficit

*Difficulties in reintegration during early adulthood, due in part to community stigma

*Frequent failure to respond adequately to the psychological needs of children

*High costs compared to community based care

*Lack of government standards and monitoring of the care provided

Currently, in sub-Saharan Africa, trends indicate that there is more donor funding for institutional care for children, and if this continues, it is most likely that families, communities and governments will opt for these facilities as a first resort for orphans. However, this may be detrimental to the children's welfare. The first options for orphans should be to promote and establish community based care as well as to formulate a framework that would support grandmothers caring for AIDS orphans (UNAIDS, 2006).

HIV/AIDS affects children emotionally, physically, and economically. The impact of AIDS on children begins when the parents become HIV positive and may include impoverishment, emotional suffering and neglect, increased burden of responsibility due to parents' illness, as well as stigma and discrimination associated with HIV/AIDS. The HIV/AIDS stigma has a negative impact on these children because it tends to reduce social support that may come from social capital, since many people are reluctant to associate with others known to have this disease. The direct impact that AIDS has on children is that they may live at risk of HIV, may live with a chronically ill parent or parents, and may be required to take on household and caring responsibilities, thereby abandoning their education. When children take on household responsibilities, they also experience role conflict. This is because while they are still children, they become heads of households and bread winners as well as fathers and mothers to their siblings. HIV/AIDS has adversely affected most of the households in sub-Saharan Africa, albeit,

it is the poorest sectors of society that are most vulnerable because they lack resources to enable them to deal with the consequences of the epidemic (UNAIDS, 2006).

Besides, AIDS also has an indirect impact on children by putting pressure and strains on the services that communities provide; for example, nurses and doctors may suffer from the disease and thereby threaten the provision of health care to the children, and teachers may fall sick and fail to teach, thus disrupting children's education (UNICEF, 2006). These factors may have a long term effect on children and may hinder their progress in life. When children lose one or both of their parents because of AIDS, they also lose their parent's social capital along with the love, nurturing and protection of biological parents which are critical to early development. Also, children have to move to a new home, sometimes more than once (UNAIDS, 2006). Loss of parental social networks means that children's sources of support will dwindle.

When parents die and children are sent to live with relatives, it is most likely that such a family may dissolve. A study in rural South Africa "suggests that households in which an adult had died from AIDS were four times more likely to dissolve than those in which no deaths had occurred" (AVERT, 2009: 2). In sub-Saharan Africa, other countries are also experiencing a similar situation; for example in Botswana, it is estimated that on average, every person who earns an income is likely to take care of at least one dependent in the next ten years because of the AIDS pandemic (AVERT, 2009).

4.2 Impact of HIV/AIDS in Zambia

The findings of this study demonstrate that in Zambia, AIDS has caused changes in family structure and imposed immense suffering on the family, especially on grandmothers as caregivers. Zambia is one of the seven sub-Saharan African countries that have been severely affected by HIV/AIDS. Others are Swaziland, Botswana, Namibia, Lesotho, South Africa, and

Zimbabwe; these countries have a prevalence rate that ranges between 16 and 35% (Chulu, 2007). In order to be able to appreciate the effects that the HIV/AIDS epidemic has had on Zambia, a brief historical background of the political and economic changes the country has gone through is necessary.

Zambia gained independence from Britain in 1964 and adopted a multiparty system of government. However, in 1972 Zambia became a one party state and began subsidising food-stuffs and providing free social services such as education and medical services to its people. The country managed to provide these free services because its economy was vibrant since the price of copper, its main export, was high. However, the economy of Zambia started deteriorating in the 1970s when the price of copper declined (Chulu, 2007).

In 1991 Zambia reintroduced a multi-party system and fully embraced the Western type of liberal democracy, which exacerbated poverty. In order to improve the economy, the government of Zambia in the early 1990s implemented the Structural Adjustment Program (SAP) supported by the World Bank and International Monetary Fund (IMF) and pursued policies and programs that facilitated private sector growth. These included removing price controls, trade liberalization, market determined exchange and interest rates. With the introduction of a liberalized market oriented economy, most of the public companies were privatized. Almost half of the companies that were privatized were liquidated because of poor management and the fact that the Zambian market was opened up to international competition without any safeguards for local firms. Even those that were not liquidated laid off most of their workers. The unfortunate part of this situation is that many people had worked for these companies for many years, but when they were laid off they did not receive any severance benefits. The implementation of SAP adversely affected the people, and poverty levels increased

to about 80% of the population, with unemployment rates ranging from 60 to 80%. This situation increased the high disease burden in Zambia and exacerbated the prevalence of HIV/AIDS. Although the government is trying to address this situation, it is being constrained by a lack of resources (Chulu, 2007).

Lewis (2005) claims that the World Bank and International Monetary Fund gave loans to Zambia with strings attached: "SAPS were driven by conditionality which included, sale of public sector corporations to the imposition of cost sharing (the euphemism for user fees imposed on health and education), to salvage cut-backs in employment levels in the public service, mostly in the social sectors" (2005: 5). The IMF placed limits on numbers of people who could be hired, such as health professionals and teachers, and also placed a limit on how much they could be paid. It is clear that Zambia could not adequately respond to the HIV epidemic, in part because of user fees in health and school fees that people could not afford. Meanwhile, as children from poor families continue to struggle for survival, children from the upper class continue to entrench their positions. This is clearly a case of role conflict because children are supposed to be in school and not working as breadwinners.

According to the Jesuit Center for Theological Reflection (JCTR) (2010), a Non Governmental Organisation (NGO) , poverty is a multidimensional phenomenon; it is not only a deprivation of material gain necessary for a decent standard of living, but a denial of opportunities and choices basic to human development. In Zambia, poverty is identified as a lack of basic needs such as food, shelter and clothing, which is a result of a lack of employment. It is common to find households, especially where there is no one in formal employment living on one meal per day or in some cases one meal every two days. However, even those who are employed may be considered to be living in poverty because of the low salaries and wages they

are paid. In 2004, Zambia's poverty rate was 68%. The government of Zambia has been reluctant over the years to provide an empirical poverty line. However, the JCTR is the only organisation in the country that conducts research and has come up with the Basic Needs Basket (BNB). The BNB highlights what it would cost for a family of six (6) to have their basic needs met; on average most Zambian families comprise six people. In August, 2010, they conducted research and concluded that for a family of six to survive for one month they need to spend on:

Table 1

Cost of food basket per month

Basic food	K 848,350
Essential non food items	K1,979,430
Total	K2,828,780
US-Dollar equivalent	$ 600

Jesuit Center for Theological Reflection Quarterly Bulletin, 2010

However, most of the Zambians who are not employed in the formal sector are unable to raise this amount. Even those who are employed face challenges; the following table shows that the salaries/wages workers receive per month are inadequate:

Table 2

 Average Salaries for Zambians

Teacher	Nurse	Guard with a security firm	Secretary in the civil service	Average Monthly Income	Piece work on a farm
K1,300,300 to K2,200,600	K1,300,000 to K3,450,000	K250,000 to K850,000	K1,390,500 to K1,900,000	K645,326	K5,000 to K15,000 per day
276 to 479.45	275.72 to 731.71	53.02 to 180.28	294.91 to 402.97	136.87	1.06 to 3.18

Jesuit Center for Theological Reflection Quarterly Bulletin, 2010

As already stated, in Zambia it is generally known that every worker supports an average of six people such as their children and dependants. It is clear therefore that most of the people live on less than a dollar per day. This is supported by the pastoral letter of 2010 written to the government by the Christian Council of Zambia (CCZ), an umbrella group of churches, stating that " The Majority of Zambians continue to live below the poverty datum line coupled with an extremely high unemployment rate" (JCTRQB, 2010: 1). CCZ attributed this state of affairs to unequal distribution of resources that have been gained from recent economic growth and the implementation of policies that have tended to give preference to foreigners at the expense of Zambians. The CCZ attribution of poverty to unequal distribution of resources is clearly in line with the conflict perspective.

HIV/AIDS has compounded the ability of Zambia to fight such high levels of poverty. It has also undermined the capacity of families to lead and enjoy a good standard of living. HIV has made it difficult, for example, for families to afford investing in their farms or to accumulate assets such as land or livestock because of distress selling and property grabbing that result or follow the death of a spouse. However, children from upper class, educated families have not been affected by property grabbing because in most cases their parents leave wills, which makes it difficult for relatives to expropriate property from them.

HIV has affected individuals, communities, and the nation as a whole. As a result, every Zambian knows a relative, friend or associate who has died of AIDS related illness. "The adage we are all either infected or affected accurately portrays the situation as it exists today" (Chulu, 2007: 9). Since HIV/AIDS has adversely affected households, Zambia's strategy to resolve the epidemic has been to utilize the family itself through home based care programs (encouraging family members to care for the chronically ill). However, since the family is unable to

adequately respond to the challenges that HIV has inflicted on it, home based care programs have tended to rely on grandmothers.

Further, poverty leads to malnutrition which is also a big challenge for people with AIDS. In fact, malnutrition, even without HIV, undermines people's immune systems. But for HIV positive persons, malnutrition is even more complex because of the added stress that is placed on an already weakened immune system which may complicate treatment. It is therefore, important for HIV positive persons to have good nutrition which obviously comes with a good income. "Good nutrition improves body weight, which reduces the incidence of opportunistic infections and increases survival in adults" (Chiwele, 2007: 21). This is why AIDS patients require good nutrition in order to be healthy, but without any source of income it becomes difficult for HIV positive people to survive. As a result, the death rate of HIV positive patients has continued to increase (Chulu, 2007).

It is important to note that in order to have a decent standard of living, one needs to have a decent job and earn a decent wage. But, in Zambia, formal employment is difficult to obtain. There are simply no jobs and as a result poverty levels are very high, and most of the people are not able to access basic needs such as food, education, health care, housing, clean drinking water, and sanitation. Just as poverty has exacerbated the incidence of HIV/AIDS, the HIV epidemic has aggravated the prevalence of poverty and has infused new dynamics into the vulnerability of households and communities. It is devastating all assets including human, financial, natural, economic, and social that families require in order to enjoy a high standard of living (Chiwele, 2007).

Furthermore, widening vulnerability due to HIV/AIDS means that people are finding it far more difficult to cope with and recover from shocks such as droughts, floods, and sudden

increases in food prices. What this means is that any gain in the fight against poverty will be transitory if there are no substantial gains in responding to HIV/AIDS. AIDS is affecting the intergenerational transfer of skills and knowledge in the management of natural resources, accumulated by communities over many years. This situation has been compounded by loss of income and labour, which means that families have few sources of livelihood. Consequently, this has led to poor management of natural resources such as bush meat (wild animals), medicinal plants, and firewood. Charcoal burning has therefore contributed to deforestation which in turn has led to soil erosion--(Wood is put in the kiln to produce charcoal or firewood which is used for cooking). AIDS has caused demand for new land to settle families putting further pressure on the environment. This is due to the fact that after the death of a husband, family members rush in to grab property such as land (Chulu, 2007). This has a negative impact on the family which is further strained emotionally, psychologically and now economically.

In Zambia, HIV/AIDS prevention and treatment is targeted at young adults. Prevention programs are aimed at reducing sexual transmission of the virus by promoting three types of behavioural change: sexual abstinence, mutually faithful monogamy among uninfected couples, and condom use for people involved in sex. The church in Zambia, in particular the Catholic Church, has strongly opposed the use of condoms claiming that it promotes promiscuity. In a way, the Catholic Church has made it difficult to popularise the use of condoms because most Catholics tend to believe the words of their priests more than anybody else.

In Zambia, the major sectors of society adversely affected by AIDS are the economy, agriculture, health, and education. These sectors have a direct bearing on the family and affect the quality of life that grandmothers and their orphaned grandchildren experience. It is therefore necessary to consider the impact of AIDS on each sector separately.

4.2.1 Impact of HIV/AIDS on the Economic Sector

The impact of AIDS on the economy has played a larger role in the reversal of human development than any other single factor. The most significant impact on development has been the destruction of the economy. HIV has damaged the economy by reducing the labour supply through increased mortality and illness. Productivity has declined because workers are sick; as a result tax revenues have fallen and government income has decreased. Consequently, the government of Zambia has been pressured to increase spending to combat the HIV epidemic yet, it has fewer economic resources to do so (AVERT, 2009).

In addition, AIDS makes labour more expensive and reduces profitability, which leads to less investment from international business. Africa and Zambia in particular have become less attractive for direct foreign investment. Thus AIDS is threatening the economic development of Zambia, but even before the advent of HIV/AIDS the Zambian economy was already struggling with major challenges, debt, and declining trade. AIDS has combined with these to worsen the situation (AVERT, 2009).

However, in 2005, the G8 leaders confirmed cancelling about US$40 billion in debt for the eighteen poorest countries; however, the actual savings for Africa was only about US one billion. Nevertheless, in response to this cancellation of debt, Zambia announced that it would use the savings to purchase antiretroviral drugs for AIDS and drugs to combat malaria (AVERT 2009). However, literature has so far not indicated if this has been done and what impact it has had on the fight against the epidemic.

4.2.2 Impact of HIV/AIDS on the Agricultural Sector

The HIV epidemic has adversely affected the agricultural sector, which is considered the hub of economic development. Families affected by the epidemic are reducing their areas under

cultivation because of a lack of labour due to chronic illness, death and time taken to attend funerals. As a result, yields are falling, and since the majority of the people depend on subsistence farming, this situation has enhanced poverty. Consequently, farming households do not have enough food and therefore lack food security. The impact that HIV has had on the agricultural sector has therefore directly affected the family (ZDHS, 2007).

In 2002-2004 the government of Zambia declared agriculture as the engine for economic growth because the sector absorbs about 67% of the country's labour force. Agriculture is also very important for urban employment as the agro-processing industries which depend on agriculture comprise about 75% of the Zambian manufacturing industry. However, HIV/AIDS has curtailed the role of the agricultural sector as a source of development. This situation has been compounded by the loss of extension workers. Many extension workers who are expected to teach farmers are also dying or are unable to work due to HIV/AIDS. As a country, Zambia has therefore had to depend on food imports which are not only expensive but also depress prices of local agricultural commodities (AVERT, 2009). This situation has tended to make the poor, poorer and the rich, richer and has exacerbated existing social and economic inequalities.

4.2.3 Impact of HIV/AIDS on the Health Sector

According to a report by AVERT (2009)**,** the AIDS pandemic has continued to put pressure on the health sector. This is because, as the epidemic spreads, the demand for health care for HIV positive people rises, as does the toll of AIDS on health workers. In sub-Saharan Africa, and Zambia in particular, it is estimated that the direct medical cost of AIDS (minus antiretroviral treatment) is about US$30 per year per person infected, yet the overall spending on a person per year is less than US$10.

The health sector in Zambia which is at the heart of the fight against HIV/AIDS has been overwhelmed by the epidemic. For example, the system is unable to isolate people suffering from tuberculosis (TB) because there are too many cases due to HIV/AIDS. As a result more people are exposed to TB since it is an airborne disease. In fact, more than half of the beds in hospitals across Zambia are occupied by HIV positive people. Subsequently, hospitals are unable to cope as a result of the shortage of bed space; most patients are admitted only in the later stages of the illness thereby reducing their chances of recovery. Thus, emphasis is placed on home based care (AVERT, 2009). Home based care is appropriate for the rich because they can afford to pay for private visitation by nurses, doctors and afford drugs. Obviously, this option is not available to the poor.

At the same time that AIDS is causing an increased demand for health services, many health care workers are also directly affected by the epidemic. "A study in one region of Zambia found that 40% of midwives were HIV positive" (AVERT, 2009: 2). Already, Zambia has a shortage of healthcare workers which has been worsened by excessive workloads and low pay resulting in most health care workers migrating to richer countries for better working conditions. This shortage of healthcare workers has been compounded by the fact that providing antiretroviral treatment requires more time and training than is currently available in Zambia. Lewis (2005: 47) argues that "the pandemic has taken a decimating toll on nurses, doctors and clinicians; it has also ravaged the ranks of community health workers, teachers, farmers—absolutely every professional discipline and other occupations." Lewis further argues that the problem is grievously compounded by the practice of poaching (poaching is the practice of Western developed countries attracting qualified personnel from developing countries) and the resulting brain drain from Africa to the outside world (Lewis, 2005).

<u>4.2.4 Impact of HIV/AIDS on the Educational Sector</u>

There is a circular relationship between AIDS and education: as the pandemic worsens, the educational sector is damaged, which in turn results in an increase of HIV transmission. "Without education, AIDS will continue its rampant spread. With AIDS out of control, education will be out of reach" (AVERT 2009: 50). Through education, people, especially children, learn how to protect themselves from AIDS by using condoms. However, without education, children will not be knowledgeable about the transmission of AIDS. Basic education is therefore a necessary tool in combating the pandemic.

However, many children from the lower class in Zambia withdraw from school for various reasons, such as to care for parents or family members who are HIV positive, or they may be HIV positive themselves. As a result, children are not aware of the dangers of HIV/AIDS. Since children lack knowledge about the dangers of AIDS and about how they can protect themselves, they are likely to be more vulnerable to contract HIV. Studies have shown that young people who are educated are more likely to prevent contracting HIV/AIDS through the use of condoms than those without education. Evidence shows that the more educated a person is, the more likely they are to change their behaviour or use a condom. The proportion with comprehensive knowledge about HIV and AIDS rises with level of education and wealth quintile among both women and men (Chulu 2007).

Notwithstanding the above, one study in Zambia, suggests that the more educated a person is, the more likely it is for them to be infected with HIV/AIDS. This is confirmed by data from women attending antenatal clinics in 1994 which shows high rates for the educated who reside in urban areas. Those with post secondary education had a prevalence rate of 42% in urban areas and 32% in rural areas, compared to 13% and 7% respectively for those with no

education (Fylkesnes, 1995 in Baylies 2002). This is contrary to most literature on the subject, as it has been proven that education helps people to protect themselves from HIV. According to Chiwele et al. (2007) the elite who are educated may be more prone to HIV/AIDS because they are likely to be mobile and live in urban areas. In most cases, as they get exposed to information on the dangers of HIV/AIDS, they are more likely to protect themselves from risky behaviour than the poor who are exposed to less information.

Furthermore, Chulu (2007: 230) argues "HIV prevalence increases with level of education. Overall 10% of people with no education are HIV positive, compared with 14% of those with a primary education, 15% among people with secondary education, and 19% among people who have more than secondary education. The same pattern is observed for both women and men" However, Chulu has not given a reason for this contradiction; it can only be assumed that this is due to the fact that the more educated a person is, the more likely he or she will be mobile and become exposed to the virus because it is more prevalent in urban areas.

HIV has also affected teachers, some of whom have died, while those who are alive take time off from work, thus depleting the already limited number of teachers available. Absenteeism of teachers is worsened by the fact that some of them have to attend funerals and care for their sick or dying relatives. When a teacher does not report for work, the class may be taken over by another teacher, may be combined with another class, or may be left untaught. However, due to the shortage of teachers, classes are usually left unattended. By negatively affecting both the supply (fewer school teachers as the result of deaths and absenteeism) and the demand (dropping enrolment and survival rates of HIV-affected pupils), HIV/AIDS is obviously complicating efforts to attain universal primary education by 2015; which is one of the Human Development Goals (MDGs) for Zambia (Chiwele, 2007).

4.2.5 Impact of HIV/AIDS on Households

AIDS affects families in three different ways. These include hosting a chronically ill patient, experiencing an AIDS related death, and caring for orphans. When chronic illness occurs participation in the labour force decreases, and there is an increase in informal caregiving and spending on health care. Death results in immediate loss of labour and can lead to changes in the structure and composition of the family which may negatively affect the availability of labour. The result may be an unsustainable response such as selling assets which ultimately may end in dissolution of a household. The decision to take on a child depends on the age, gender, and skills that the orphan brings which may determine the overall contribution of the orphan to the household. This means that orphans who have no skills and are likely not to contribute to the household end up on the streets fending for themselves or selling foodstuff on behalf of the household in order to be useful. In the end, children from poor families have to drop out of school (Chiwele et al. 2007). This situation perpetuates social and educational inequalities as far as the conflict perspective is concerned.

When people are sick, it is a strain on the family members who take care of them and it is also a strain on household resources. Households are pushed deeper into poverty due to loss of income, additional care related expenses, the reduced ability of caregivers to work, and mounting medical fees. The death of a sick person aggravates poverty in the family. This is because in Zambia, funeral insurance has just been introduced and it is only available to a few rich people who are able to pay for it. Besides, the financial burden on the family of providing home based care imposes demands on the physical, mental, and general health of caregivers (AVERT, 2007). The conflict perspective observes that this is common among the poor who have limited resources.

When one parent dies, orphans typically live with the surviving parent. However, a review of household data by UNICEF (2004) found that female headed households are more likely to care for orphans than male headed households. This is all the more reason why grandmothers and not grandfathers seem to be prominent in caring for AIDS orphans. Although this review of household data did not explain why this is the case, it can be assumed that this may be attributed to the patriarchal culture that dominates most African states, which requires that females care for children and the sick while males merely provide economic resources. For example, in Kenya 51% of orphans are being raised by grandparents, in particular grandmothers (UNICEF, 2006).

4.2.6 Impact of HIV/AIDS on Children

HIV/AIDS has lead to the mushrooming of both grandmother and child headed households. While it is apparent grandmothers heading households experience role conflict and role overload, it is clear that children heading households also experience role changes and role overload. This is because while they are still children, they are called upon to provide resources and care for other children. As household heads, children are expected to generate income, provide food, accommodation, and take care of household chores. These responsibilities are not only stressful and difficult to fulfill but are also insurmountable (Piprell, 2003). In Zambia just like other countries, children affected by HIV/AIDS go through tremendous trauma and hardship because of role conflict and a lack of social capital. Since orphaned children play various roles, they are overloaded with many responsibilities resulting in their failure to fully fulfil any of them leading to role strain. The situation is compounded by the loss of their parent's social capital due to stigmatization which is associated with the epidemic. The epidemic not only causes children to see their parents dying but to lose their childhood as well. When family members become ill

before the children mature, children from poor families are called upon to take on more responsibilities (AVERT, 2009).

Children who are orphaned by AIDS suffer extreme emotional turmoil because they do not become orphans when their parents die, but while their parents are dying; this is especially true when it is their mother who dies. The situation is gloomy when grandmothers die too, as there is no one else to step into their roles. Therefore, the oldest child becomes the head of the household. In Zambia, where 23% of all children are orphans, most of them are living in child headed households. In the absence of parents, the schools are the best institutions to socialize AIDS orphans, but the problem is that the children lack resources to continue with their education. It is therefore apparent that without social support these orphans may end up uneducated, alienated, unsocialized, and on the streets (Lewis, 2005). Lack of social capital aggravates lives of orphans who have no opportunity to interact with other children due to work obligations and/or inability to afford to go to school; as a result they have no hope of changing their status by moving upwards on the social stratification ladder.

One of the major impacts of AIDS on orphans in Zambia has been to compel children to work. Jobs include either working on the streets or in markets. Working on the streets (vending) involves selling merchandise, either for themselves or for others, including foodstuff such as vegetables, fruits, second hand and new clothes, toys and newspapers. Children are also involved in quarrying and stone breaking, fetching water, pottering, household chores and domestic work, digging wells and garbage pits, carpentry, cooking nshima (thick porridge made from maize meal) in the markets, cutting glass, picking bottles and prostitution (Chiwele, 2007). These responsibilities are a recipe for role strain and role overload for the children as they are too busy working to stay in school and to be socialized with other children.

According to a study conducted by Mushingeh et al. (2002: 12) on the impact of HIV/AIDS in Zambia, it was concluded that the death of parents or guardians promoted child labour. HIV/AIDS has often compelled orphans to engage in prostitution and other forms of dangerous work on the streets where they are exploited. This research was conducted in three provinces in Zambia: Copperbelt, Lusaka, and Eastern. The sample of child labourers included 211 boys and 95 girls ranging in age from 5 to 16. A combination of focus group discussions and personal interviews were used to collect the data. Although the sample size was relatively small, the results clearly confirm what other researchers have stated before that HIV has adversely affected children lives. Mushingeh, et al. (2002: 3) also contend that "child labourers were found everywhere: in markets, streets, bars and pubs, shopping centres, bus stops, car parks, rest houses and hotels." In fact, this study also states that "only about twenty two (22%) of child labourers were HIV/AIDS orphans: the main reason that children are involved in work is due to lack of resources such as income by their respective families" This situation supports the conflict perspective which argues that the poor have to sell their labour in order to pay for their basic needs and reinforces the never ending cycle of poverty**.** Yet, children are supposed to be in school and not breadwinners; working is therefore in conflict with children's development and is a strain on their abilities and energy.

It is apparent that children are exploited in their work as payments are usually very low; for instance, child porters who carry goods (mostly on their heads) such as bags of maize meal, bundles of sugar cane, luggage, water buckets, firewood, and other items are paid K100 (equivalent to US$0.02) per load. Some of the work children perform is in the family interest; as a result, they are never paid. On average, they work for 8 hours per day, so as a result they

cannot go to school (Mushingeh, et al. 2002). The conflict perspective would attribute this scenario to inequalities in society.

In most cases, even those who work as prostitutes do so to raise money to support their families. However, payments for prostitution are equally low; in some cases the children are merely given beer or second hand clothes. Many of the children who are involved in prostitution have no control over their clients; therefore, they risk contracting HIV/AIDS because of the patriarchal Zambian culture which makes it difficult for them to negotiate the use of condoms with predominantly male customers**.** Children involved in labour are also at risk of diseases and injuries, and when they are sick, they have no access to health facilities because they lack resources/income. Subsequently, they tend to allow the disease or injury to heal itself. Mushingeh et al. (2002: 14) argues that "almost every job performed by children included some kind of health risk, and a large majority of working children suffer poor health." Of interest is the fact that only children from the poor, low class families are involved in child labour.

As indicated earlier, the total number of orphans in Zambia is about one million two hundred thousand, yet orphanages, foster homes, and group homes are only able to care for five thousand (5000) orphans. Since grandmothers only care for about 43% of orphans, it simply means that most of the orphans have to either live on their own or on the streets. It is therefore clear that many of these orphans have no future, since they lack education and the necessary skills to enable them attain a good quality of life. In fact, they are not able to fully contribute to the labour force and it is most likely that they will be a burden to the nation.

Previously, orphans may have relied on the extended family, neighbours or community for support, but now this type of support is unsustainable. Studies conducted in Malawi, Rwanda, Zambia, and Zimbabwe found that orphans living with chronically ill caregivers lack basic needs

such as blankets, shoes, and extra clothing Mushingeh et al. (2002). The study also states that orphans who had migrated to another household reported being given different food from other children in the same house, being overworked, beaten, and given inadequate clothing. An analysis of demographic and health surveys in the ten sub-Saharan countries found that orphans are also discriminated against as less investment is spent on their education compared to others in the same household (UNICEF, 2006). Orphans are always the last to be sent to school when finances are not adequate in the household in which they are receiving care. This explains why they have lower enrolment rates in schools. Since orphans lack the financial support necessary for them to continue their education, they resort to working and abandon school, and consequently face challenges of role conflict as discussed earlier.

4.2.7 Impact of HIV/AIDS on Grandmothers

In 2001, during the United Nations General Assembly Special Session (UNGASS), on HIV/AIDS 189 United Nations member states signed and adopted the declaration of commitment to halt and reverse the HIV/AIDS epidemic by 2015. In 2006, the same countries renewed their commitment by adopting and signing a political declaration in which they promised to provide universal treatment, care, and support to people afflicted by the epidemic by 2010. This is the UN's framework that helps to gauge a country's commitment to fight the HIV epidemic (Sidibe, 2009).

However, although older people are both affected by and infected with HIV/AIDS through their role as caregivers, they are conspicuous by their absence since no mention was made about them in the two declarations. Further, studies have shown that older people are not included in AIDS educational programs world-wide. For instance, an analysis by HelpAge International of United Nations General Assembly Special Session on HIV/AIDS (UNGASS)

reports from Ethiopia, Mozambique, South Africa, Tanzania, Uganda, Zambia, and Zimbabwe indicates that older people are not included in the programs to combat the HIV pandemic. "Older people are often discriminated against in the provision of HIV and AIDS services because of a wrongly held assumption that older people are not sexually active, and that HIV only affects younger people (UNAIDS, 2006 in HelpAge, 2008: 2). However, from a conflict perspective, grandmothers are excluded from HIV/AIDS programs because they are a weak vulnerable group lacking power and resources to have their concerns raised in a national discussion on HIV/AIDS and its social impact. As a consequence, there is a lack of knowledge about the effect of HIV/AIDS on their lives. It is therefore clear that progress in combating HIV/AIDS cannot be made because of the exclusion of older people from policy and program responses to the epidemic.

Since grandmothers as caregivers are not targeted in HIV prevention programs, they are susceptible to many challenges. They experience lower levels of life satisfaction and high levels of poverty, which leads them to be more exposed to depressive symptoms. Burnett (1999, in Fuller-Thomson 2005), holds that grandparents may have low self-esteem because they are strained by the many roles they are expected to play at a late stage in their life. The experience of grandmothers is aggravated by the fact that there is a lack of preparation for them to undertake caregiving for their grandchildren. "Furthermore, the emotional, physical, and economic toll of raising multiple grandchildren appears to be particularly acute" (Minkler & Roe, 1993, in Fuller-Thomson 2005: 338). As grandmothers in skipped generation families, their responsibilities include that of homemakers, parents to adult children (most of whom are HIV positive), spouses, employees and business women (street vendors). As well as filling their traditional role as grandmothers, they are expected to help their grandchildren with homework, teach them

traditional values, and prepare them for life. In most cases, grandmothers have no spouse to help them; as such, they are expected to play the role of a mother as well as a father (Fuller-Thomson 2005). Practically, this is impossible as grandmothers encounter problems of role strain and role over load, that is, they face problems in meeting all of the expectations associated with their various roles. These challenges that grandmothers face are not unique to a particular country or culture, they are universal.

As the main caregivers, grandmothers have many responsibilities. They are required to pay for treatment, food, and transportation. When a person who is HIV positive is being cared for at home, grandmothers are also expected to provide meals to guests. In almost all cases they are also expected to shoulder the expenses of funerals when the person dies. However, in some cases family members contribute to the cost of caring for the patient as well as to the cost of a funeral. Of interest is the fact that governments do not encourage hospitals to provide long term care for people who are HIV positive. The end result is that grandmothers face a major challenge of role overload and role strain because of the many various responsibilities they have and consequently, their life is unfulfilled (Knodel 2005).

One of the major challenges faced by grandmothers caring for an HIV positive person is doing laundry for the patient. During the advanced stage of the illness, grandmothers are called upon to clean bedding which is soiled by either urine or excrement, thus adding a very unpleasant dimension to the cleaning process. This situation is emotionally and physically straining for both grandmothers and the patient (Knodel and Saengtienchai 2005). Even when a person is admitted to a hospital, grandmothers still have to provide care such as taking the patient to the bathroom, turning them in bed, and cleaning them. This is particularly stressful for the caregivers because they have to provide this kind of support on a 24 hour basis due to the fact

that hospitals have a shortage of staff. In most cases, it may be better for the patient to be cared for at home because the caregiver may be able to sleep in his or her bed, unlike sleeping on the hospital floor. Only grandmothers from poor families who cannot afford to pay for external help go through this experience, since the rich do not send their patients to government hospitals but to private hospitals. The conflict perspective is clearly supported by the fact that the rich and powerful do not have to perform such unpleasant tasks because they are likely to have access to better care.

The most devastating issue of grandparenting is the isolation and lack of social support that comes with caring for a person who is HIV positive and grandmothers' failure to provide for their grandchildren. Most of the research conducted in this area highlights the fact that grandparents are at a stage in their life when they experience an 'empty nest' because all their children may have already left home. This may explain why grandmothers struggle with caring for their children who are afflicted with HIV, and find it a challenge to provide for their grandchildren (Baranyai 2000). Consistent with the role conflict framework, grandmothers' failure to meet primary needs for their dependents leads to anger, fear, sadness, shame, and poor quality of life.

Fuller-Thomson (2005) notes that grandparents' caregiving is universal, but grandmothers in various parts of the world provide care for different reasons. For example, in Canada, grandparents provide care to their grandchildren in response to a crisis such as imprisonment of the children's parents, alcohol, and drug addiction. However, among the Ojibwe tribe, paternal grandparents are honoured by co-parenting their grandchildren with the children's parents. The main reason for co-parenting is to allow the grandparent to transmit traditional values to the children. In Canada, there is hope that one day the parents of children may relieve

grandparents from the burden of caring for children, while in Zambia this is not the case, as grandmothers care for their grandchildren because their parents have died, (Fuller-Thomson, 2005).

Although grandmothers derive some satisfaction from caring for their orphaned grandchildren, it is clear that they experience a number of psychological and economic stressors that cancel the benefits of caring (Burton 1992 in Baranyai 2000). In addition, Minkler and Roe (1994, in Baranyai, 2000) argue that grandparent caregivers feel challenged by the loss of freedom and being moved backwards by the responsibilities of parenting in their old age.

It is important to recognise that grandmothers are preoccupied trying to meet basic needs such as food, shelter, water, clothing, rest and sleep. They are, therefore, not in a position to address secondary needs (such as safety, belonging, esteem, and self actualisation) until their primary needs are satisfied. This is in line with Maslow's Hierarchy of Needs, which contends that an individual will only aspire to higher needs after basic needs have been met (Maslow, 1970). Since grandmothers cannot meet secondary needs, they are therefore not able to establish social capital and access the benefits of social support.

4.2.8 Challenges to Family Systems

According to the UNICEF/UNAIDS estimates, at the end of 2006, 17% of the people in Zambia aged 15-49 were living with HIV or AIDS. Of these adults, 57% were women. A United Nations International Children's Education Fund (2007: 2) report indicates that Zambia has the "highest proportion of orphaned children in the world. An estimated 23% of all children less than 15 years are missing one or both parents, many of them dead from AIDS, and by the end of 2007 there were over 700,000 AIDS orphans in Zambia." This means that women and children are more adversely affected by HIV/AIDS. AIDS orphans are more likely to drop out of school than

non-orphans for various reasons, such as lack of school fees, the need to assist with household chores, stigma, or indeed the need to stay home to care for sick parents or young siblings (Poku, 2005). In addition, research conducted in 2005 by Young and Gander (cited in De Witt, 2007: 5) confirms this and indicates that; "Orphans and vulnerable children are disadvantaged and as such are least likely to be in school, have access to health care, receive meals, have basic needs met, be receiving psychosocial or other support, and have their births registered." As far as the conflict perspective is concerned, inequality in accessing services and resources puts these children from poor families at a disadvantage.

The overall impact of HIV/AIDS is that most major services may grind to a halt, while people's standard of living deteriorates along with continuous escalation of poverty and hunger. At the family level, if one or both parents die while children are still young, it means that the parents are unable to transmit knowledge and culture to their children. In most cases it also leaves the orphans destitute. Owing to the lack of resources, most of them withdraw from school. Consequently, the potential for inequality among this generation of young people and their families increases. It therefore becomes difficult for HIV/AIDS orphans to access education; as a result it is impossible for them to move upwards on the social stratification ladder.

This situation is exacerbated by the lack of financial resources among lower class families who go deeper into poverty. Therefore, poverty adversely affects these families, contributes to a lack confidence and feeling hopeless and results in high levels of distress. In order to deal with this situation these family members may engage in risk behaviours; for example, girls become prostitutes so their chances of getting infected by AIDS increase. Boys become criminals which makes them susceptible to arrest. In this case, the behaviour of girls and boys supports the conflict perspective, especially the concept of deviance. As children from poor

families are involved in these deviant activities in order to survive, the children from rich families continue pursuing their education; consequently, they are able to get well paying jobs and retain their position on the social hierarchy, while most of the children from poor families obtain low paying jobs and have little chance of upward mobility.

Many orphans, after losing their parents, also lose their inheritance as relatives quickly swoop in and grab property, be it cooking pots or farm land. Although they could appeal to the courts, few Zambians have the necessary means, such as money to do so. In order to survive, some children stop going to school and end up on the streets, boys become beggars and petty thieves, while girls become involved in prostitution. According to Dr. Mannassah Phiri (no relationship with the researcher), an AIDS activist, "before the HIV pandemic, street children were a very rare sight in Zambian cities, now they are everywhere sleeping under bridges, behind walls and in shop corridors" (AVERT, 2008: 3). Steven Dahlgren, a project officer with UNICEF based in Zambia contends that child abuse, child labour and sexual abuse have aggravated the situation (Daley, 1998). The defilement (sexual abuse) of girls is attributed to traditional beliefs perpetuated by traditional healers, that if an HIV positive adult has sex with a baby or virgin, sero-conversion take place, that is, the HIV positive is reversed. To this end, men are targeting increasingly younger partners whom they assume to be HIV negative and virgins. Many of the abusers are HIV positive and many transmit their infection to their victims.

The extended family system, which in the past served as a safety net to care for orphaned children, has been stretched by HIV/AIDS to the point that it is unable to cope. The responsibility of caring for AIDS orphans has continued to fall on grandparents, especially grandmothers who are struggling with the burden of feeding and clothing their grandchildren. Fouad (2005: 16) emphasizes the fact that "both caregivers and orphans are in great need of

support. Orphans need physical, emotional, and psychological support, educational and vocational skills, health care, and assistance in coping with and/or avoiding stigmatization, exploitation, and socialization. Conversely, grandmothers need child care, labour and vocational skills, legal advice and assistance, health care, and psychosocial support."

In the past, the structure of a typical Zambian extended family made it possible to care for children who had lost their parents. Such a family was comprised of children, parents (father and mother), uncles, aunties, brothers, sisters and grandparents. It was normal in this extended family for children to have more than one father and mother. This is because the father's brothers are also fathers to the children, while the mother's sisters are mothers to the children. Uncles are the mother's biological brothers, while aunties are the sisters to biological fathers. Even when children lost one or both of their parents, though the children were referred to as orphans, to some extent they were not, as the brothers of their father automatically became their fathers; and they shouldered all the responsibility of taking care of the children. As a result, if the mother's sister inherited the children, her husband became the father to the children. In this sense, children were not orphans per se. In fact, if the extended family was facing challenges to look after the children, it was the responsibility of the village or community as a whole to provide for the children's needs. Although children were not able to get the love and have relationships that biological fathers and mothers would provide, the extended family was able to take care of children's needs more adequately than grandmothers today. However, HIV/AIDS has destroyed all this. The extended family lacks resources to care for orphans; therefore, it has dispersed and the nuclear family (comprising father, mother and children) has instead gained pre-eminence. However, even the structure of the nuclear family has also changed as most families are now headed by grandmothers and children.

In Zambia, the traditional family played an important role in the socialization of children and was seen as an important source of social security. Members of the traditional family were responsible for protecting children, the poor, and the sick, and were also responsible for transmission of traditional values and education. Uncles trained boys how to hunt, farm, and fish and imparted traditional values and customs, while aunties trained girls in household chores and prepared them for marriage. In most cases, uncles and aunties looked after and educated their nephews and nieces just like their own children. The role of grandparents was only to provide direction to their grandchildren on issues of marriage and other customs. They were not responsible for providing basic needs such as clothing, food, shelter or indeed paying for their education. However, due to social and economic changes such as migratory labour, demographic change, and assimilation of Western culture, as well as the socioeconomic impact of the HIV/AIDS epidemic, the extended family can no longer play its traditional role (Foster et al., 1997; as cited in De Witt, 2007).

Socialization of children in all cultures, and particularly in Zambian culture, takes place mainly through social observation and imitation of parents and other members of the nuclear and extended families. Parents help to control the behaviour of children by choosing the social influences that they can control such as books, friends, music, youth organizations and recreational pursuits of their children. In essence parents, uncles, aunties shoulder this responsibility. These activities are not part of the role of grandparents. However, HIV/AIDS has continued to compel grandparents to take over these responsibilities leading to role over load and role conflict (Mwamwenda, 1995).

It is clear the extended family system is desperate since the Ministry of Community Development and Social Services, as well as the Ministry of Youth and Child Development

which are responsible for coordinating and supporting children's issues in the country do not have the capacity to do so due to a lack of resources. Unlike the Western world where social welfare schemes and foster homes are able to cope with such a situation, in Zambia formal structures are not able to handle the problem, because the orphanages and foster homes are not adequate to care for all orphans. Consequently, as mentioned earlier, the responsibility falls on the surviving relatives and in particular grandparents, who are equally unable to care for and meet the basic needs of the children due to a lack of resources.

As already indicated, in Zambian culture, older people depend on their children for support and provision of basic needs such as food and clothing. However, HIV is claiming the lives of the most productive working age cohort, which is supposed to provide resources for both children and older people. It is therefore understandable why grandparents are struggling to provide for their grandchildren. To a great extent, the inability of grandmothers to care for their grandchildren can be attributed to their exclusion from HIV/AIDS programs.

In the past the extended family was the traditional source of social security in most parts of Africa, and Zambia in particular. Its members protected and cared for the children, the poor, and the sick, and were responsible for transmission of traditional values, education, and facilitating the growth of children. "Traditional methods of instructions were oral narratives, including myths, fables, legends, riddles, lullabies and proverbs. Mothers used lullabies as a means of instructions by singing daily; the children could assimilate these early teachings without strain" (Wane, & Kavuma, 2001: 5). However, for special instructions such as sexual education, children or young adults were taken away to a secluded place where they were taught morals, appropriate sexual behaviour, sexual taboos, and dangers of premarital and extra marital sex. These teachings were so effective that cases of premarital or extramarital sexual encounters

were very rare (UNICEF, 2005 in De Witt, 2007). The extended family was responsible for providing this kind of education to both young men and women. The breakdown of the extended family which is attributed in part to HIV/AIDS has eroded the capacity of the family to pass on knowledge, values and norms to the younger generations. The end result has been the spread of HIV/AIDS due to uncontrollable sexual behaviour (Wane, & Kavuma, 2001).

Although the extended family, especially grandmothers continue to be a pivotal social welfare mechanism, they face increasing challenges in their role. This is because it is clear that AIDS has overwhelmed the capacities of families, households, and communities which have been aggravated by poverty (UNICEF, 2006). Before the AIDS epidemic, grandparents had a special place in the family and were central to the life of their grandchildren. They were responsible for imparting traditional values to their grandchildren and were not required to work to support them. However, the HIV pandemic has redefined their role to include provision of basic needs (Wane, & Kavuma, 2001). Poverty is therefore more likely to increase as AIDS strips families of their assets and income earners (AVERT 2009).

4.2.9 Challenges Faced by Grandmothers

Grandparents have needs that are unique to their age cohort. However, since these needs are not well understood they are seldom met. Nevertheless, older people make positive contributions to society, including the transfer of knowledge and skills to younger generations (Wells, 2005 in Samuels & Wells, 2009). HIV/AIDS that kills the most productive age group (15-49) also affects grandmothers as it has led to an increase in skipped-generation households (SGHS)-households comprising the old and the young. Grandmothers care for their HIV positive children, and for orphans they leave behind at a time when grandmothers expect to be supported and cared for by their own children. According to Samuels and Wells (2009), it is likely that the

SGHS structure/composition may increase due to the HIV/AIDS epidemic. However, there is a lack of information about how such households are able to cope with life. In their research on skipped-generation households in Uganda and Zimbabwe, Samuels and Wells found that old age led to a decrease in the quality of health and in physical abilities, resulting in challenges to generate income and other resources.

Consequently, the burden is placed on children to raise the resources to support the family. Even though grandparents lack resources to enable them to care for their grandchildren, research shows that children prefer to live with grandparents rather than other relatives, because grandparents are more likely to love and treat the children better. Meanwhile, attempts by grandparents to get help from the extended family often yield negative results as the HIV epidemic has eroded family and community support. "In the past, grandparents were not care givers, said one grandfather from Uganda, they were teachers. They shared stories about ways to live and behave, but this is very different from becoming like a parent" (Samuels & Wells 2009: 3).

On another note, Knodel and Saengtienchai (2001 in Knodel and Saengtienchai 2005) observe that in Thailand there are three methods that lead to persons with HIV and AIDS being cared for by their parents. First, the person with HIV and AIDS (PHA) may already be living with the parents. Second, the child only returns to live with parents after being diagnosed as HIV positive, and third, the parent may travel to where the adult child is living to provide care and support. These are the same routes that parents in Zambia use to care and support their adult sons and daughters who are HIV positive. Most of the people who are HIV positive return to their parents' home to be cared for because in the Zambian culture, parents feel obliged to ensure their children's well being (Williams, Bennet, Hammavanh, & Salazar, 2006). Meanwhile, in

Thailand between 32% and 40% of adult children who are cared for by parents had returned from somewhere else. However, in Zambia this kind of data is not available because of the paucity of studies in this area. A study in Uganda, Ethiopia, Malawi, Zimbabwe, Thailand and Zambia confirms that parents, typically grandmothers, play a significant role in caring for persons with HIV and AIDS (Knodel and Saengtienchai 2005).

It is important to recognise that older people are primary caregivers both for their adult children who are HIV positive as well as for AIDS orphans. For example, in some communities in Mozambique, older people care for about 54% of orphaned children. A study in Cambodia and Thailand found that 62% and 70% respectively of older people, in particular grandmothers, care for a child in their lifetime. Since older people care for the younger generation, they are expected to educate children and youths on the dangers of HIV, but they are not able to do so because they lack knowledge. It is therefore obvious that older people are also at risk of HIV infections due to the fact that they are not knowledgeable about the dangers of HIV/AIDS. This is because the mode of transmission among older adults is the same as that for the younger people: heterosexual sex, having unprotected sex, multiple sexual partners, intergenerational sex and to some extent through drug abuse (HelpAge 2008). The inability of grandmothers to help their children and grandchildren causes stress and strain in their lives.

For instance in 2001, Kahana and Kahana conducted a qualitative secondary study entitled "Successful Aging among People with HIV/AIDS." The objective of the study was to use their "successful aging model" and show that it can be applied to disabled and chronically ill populations of older adults, including persons who are HIV positive. The main sources of their data were gerontology journal articles. In their model of successful aging, in particular for people with HIV/AIDS, they argue that social and psychological stressors are the major factors that

undermine people's ability to enjoy a good quality of life. Therefore, stress, strain, lack of social activities and relationships cause grandmothers to have a poor quality of life.

In Zambia, older adults are often not targeted by HIV/AIDS programs, yet it has continued to directly and indirectly affect their lives; as a result they experience isolation, poverty and lack of support. According to the International Plan of Action on Aging (IPAA), (2002, cited in Fouad, 2005), HIV/AIDS affects and infects older people as well. They face risks when they care for those who are infected, and when they are sexually active. Older women often in severe poverty nurse their dying children and care for their orphaned grandchildren. In addition, Wilson and Adamchak (2001: 23) argue that "unprotected manipulation at child birth may be a risk for traditional midwifery, customarily the role of the older women." Christine Oppong a researcher (as cited, in the Stephen Lewis Fact Sheet, 2007), argues that even though grandmothers may not be the majority of those infected with HIV, they are deeply affected by its social and economic implications. This is so because they are the ones who care for the sick, prime-age adults and the children left behind. Though many older men remain sexually active and take on younger partners, their vulnerability to HIV does not come to the fore as they continue to be omitted from HIV/AIDS programs. The situation in which grandmothers find themselves is partly a result of a lack of social capital.

Despite the fact that older women are the primary caregivers for their children who may be HIV positive, and are left with the responsibility of caring for their orphaned grandchildren, they are not recognised or supported by policies such as HIV intervention programs. In fact, they are often in need of care themselves, but without any support or resources, they face the costs and emotional stress of nursing the terminally ill, paying for burials and the financial burden of bringing up orphans. HIV continues to put pressure on older adults at a time when they lack

resources.   This is because in the planning and intervention programs in Zambia, the focus has been on the 15-49 age cohort thereby neglecting grandparents. As a result, they continue to experience isolation, poverty, and a lack of support. Also, older adults, especially women experience discrimination in inheritance and marriage issues.

The unfortunate part of this phenomenon is that grandparents' risk of HIV/AIDS, by direct or indirect infections, does not seem to attract the attention that it deserves. This situation is exacerbated by the common myth that older people are neither interested in nor participate in sex. This is contrary to reality as, for instance, Wooten-Bieski (1999: 268) argues that "elders do engage in sexual activities and find sexual expression to be an important and satisfying part of their lives." As a result, they, like everyone else who has sex, are prone to contracting sexually transmitted diseases including HIV and AIDS. Further, many elders are not free to discuss issues of sexuality. The situation is aggravated by lack of knowledge about elder's sex practices by health care providers who may also have no experience in discussing sexual related issues with older adults. Subsequently, diagnoses and treatment of STIs and HIV/AIDS may go unrecognised in older people, jeopardising the health of older adults and their partners (Wooten-Bieski, 1999). Older adults are almost universally omitted from HIV prevention programs and as a result they lack information compared to others who are at risk (Linsk, 1999).

Wilson and Adamchak (2001)   call AIDS 'the grandmothers' disease.' This has come about as a result of the prevailing situation in which grandmothers have taken up the responsibility of caring for grandchildren following the death of their parents. For example, in Zimbabwe, in 1997, 43% of households with AIDS orphans were headed by grandmothers. It is important to understand the environment and conditions in which they are living because these older Africans are left with this responsibility without any resources, and their susceptibility to

AIDS is an issue that has never been discussed. Wilson and Adamchak (2001: 8) also indicate that, "grandparents without any social support are called on to care for and support HIV/AIDS infected ailing and dying children and orphaned grandchildren, who may also be dying from HIV. Meanwhile, in Zambia HIV/AIDS substantially enhances the financial burden of the aged, at a time they can least afford it."

Lewis (2007) contends that older parents or relatives care for about 70 to 80% of those suffering from HIV and are dying. In Africa, and Zambia in particular, those suffering from HIV/AIDS return to their parents' home to live their final days, but it is elderly women who are compelled to take care of them and in some cases they even give up their paid work. Most of these women have lost everything and are traumatised by the loss and suffering. They are robbed of income earners and are forced into parenting again in old age. They survive through scrounging for finances for funerals, for school fees, for food and for medicine. This financial burden is very difficult for them to surmount.

Furthermore, there is a strong potential for all grandmother caregivers to experience both role conflict and role overload. This is in view of the fact that many grandmothers in skipped generation families are attempting to fulfill various kinds of obligations such as homemakers, spouses, parents to adult children (many of whom are incapacitated by HIV/AIDS) in addition to their custodial grandparenting role (Fuller-Thomson, 2005). This situation is obviously stressful for grandmothers who are neither prepared nor trained to take care of HIV/AIDS orphans. Many of them are overloaded with too many roles which obviously they are incapable of fully meeting due to a lack of resources and training. At the same time, they are also expected to equally meet their own emotional, physical, social, and psychological needs. It is apparent that many grandmothers are ill prepared for this level of involvement and the intensity of the demands

associated with their overwhelming conflicting roles which are aggravated by a lack of social support. This situation is compounded by gender discrimination, age discrimination, lack of education, and limited access to formal medical services. Lewis (2008: 69) contends that "Grandmothers have come to symbolise a world of hope for countless numbers of children orphaned by HIV/AIDS. If grandmothers were not available, what would have become of the children of our children?"

Lewis (2007: 1) observes that "A grandmother buries her own children, weeps for the loss. And then picks up and looks after the grandchildren as if it was the most normal thing in the world to do." He goes further to recount the concerns voiced at meetings with grandmothers across the African continent: "They stand up and they say, we buried three children, we have seven grandchildren. We need food. [The children] can't go to school because we can't afford the uniforms. And the next one stands up and says I buried two children. My husband has died. I am all alone. I have seven grandchildren" (the Stephen Lewis Foundation- Fact Sheet, 2007: 1). At long last, grandmothers' contribution in the fight against AIDS is being recognised, as the 2008 United Nations Secretary General's report acknowledged their role in the fight against AIDS. In response, (Lewis, 2008: 2) observes that, "curiously, there's only passing reference to grandmothers in the document. But, in an odd way, that's progress of sorts because grandmothers have never been mentioned before. Finally, if slowly, it is beginning to be realized that grandmothers are more and more the anchor for communities and their children in the midst of this HIV/AIDS pandemic."

CHAPTER FIVE – DISCUSSION: MEETING THE NEEDS OF HIV/AIDS AFFECTED FAMILIES

This chapter presents a discussion of the results of the study. It begins by highlighting the invisibility of older adults in HIV/AIDS programs; explores the experiences of HIV/AIDS affected and infected people, and Zambia's response to the epidemic. It also shows the contribution of the study to understanding the issues related to HIV/AIDS in Zambia and ends by acknowledging the limitation of the research.

5.1 Invisibility of Older Adults

The impact that AIDS has had on older people has largely been overlooked. For example, in Africa, and Zambia in particular, there is very little assistance for persons who are HIV positive, but no financial or social support is available for their caregivers. Grandparents are expected to provide for their AIDS afflicted children and support themselves. It is therefore clear why grandmothers continue to encounter challenges as caregivers (Ferreira 2004). Chiwele, (2007: 62) argues that "although Zambia has developed a lot of innovative programmes in the health sector, especially in the area of prevention, care and support, very little effort has been directed at addressing social issues and in particular, mitigating the impact of HIV and AIDS on households and communities, who are mostly affected by not only HIV and AIDS but the social ramifications of the epidemic." This situation can be attributed to the fact that grandmother caregivers are older women who lack resources and power. From a conflict perspective, it could be argued that this is the main reason why grandmothers have been neglected and ignored in both formal and informal programs intended to tackle the HIV epidemic.

Moreover, the number of older adults living with HIV/AIDS has continued to increase world-wide as a result of the antiretroviral therapies which have helped to extend their lives. Therefore, not only will some older adults become newly infected with HIV, but the number of

long term survivors will continue to increase. For instance, according to the Centre for Disease Control and Prevention (CDC) of the US, between 2001 and 2007 the estimated number of persons 50 years of age and older living with HIV/AIDS in the US increased from 65,445 to 156,511 (CDC, 2009 in Emlet, 2006)**.** In Zambia such data are unavailable. Despite these high figures, it is interesting to note that both in the USA and Zambia older adults are still not included in educational programs on how to protect themselves from contracting HIV/AIDS. This exclusion of older adults implies that they are not able to interact with others; consequently they are unable to establish social capital and benefit from social support.

As mentioned earlier, the problem is that older people have continued to be excluded from HIV/AIDS programs because it is believed that they are not sexually active. Consequently, grandmothers just like other older adults are prone to contracting sexually transmitted diseases including HIV and AIDS. In a study by Williams et al. (2003), they found that in a sample of 745 women, aged 55 and older, 98% believed that their probability of contracting HIV was zero. This is in spite of the fact that most of these women were still sexually active. This shows that older adults have continued to have unprotected sex because they lack information as they are excluded from HIV prevention programs.

Indeed, as women get older their sexuality decreases, although women still regard sex as an important aspect of their lives and continue to be sexually active. In fact, the only time that they are not sexually active is usually due to a lack of a partner or because they have a limiting medical condition. As a result of freedom from worry about unintended pregnancy, older women may not use contraceptives such as condoms during intercourse, thereby increasing the risk of infection (Emlet and Farkes, 2001).

In addition, prevention of HIV among older women is difficult because they grew up in an era when sexuality was not openly discussed, as well as the fact that the patriarchal culture that dominates Zambia and indeed most African states makes it difficult for women to say no to unprotected sex with their partner. It is therefore difficult for older women to negotiate condom use or even discuss HIV risk practices with their partners. In fact, most women believe that asking a partner to use a condom means that she believes he is unfaithful; consequently, many women engage in unprotected sex with their male partners hoping that their partners will not engage in risky sexual behaviour (Keigher, et al. 2004). This situation puts older women at risk of infection. Keigher, (2004: 71) contends that "older women, just like older men, also face a stigma stemming from embarrassment of having grey hair and still being sexually active. Thus, stigma acts as a barrier for older women, since they face a double stigma of ageism and the idea that older people should not be having sex."

All over the world, many families would not survive without the support and contributions of older adults. They care for orphans as well as provide incomes to households. However, older people continue to be discriminated against in the provision of services. The problem of HIV among older women is real and requires urgent attention. As long as older women continue to be marginalised, they will continue getting infected with HIV.

In Africa, older men and women continue to contribute to their families and communities. Yet, older people have not benefited from growth and economic development. However, even in this situation grandmothers have been resilient in caring for their adult children and grandchildren. They have done so with literally no support from their respective governments or communities (Stanley, 2008). The situation in which grandmothers find themselves is consistent with the concept of individualism as outlined by the conflict perspective. Individualism suggests

that the challenges grandmothers are facing should be resolved at the micro rather than the macro level; subsequently grandmothers are blamed for their vulnerable status and not the impact of structured social inequality.

Furthermore, Stanley (2008) reports that it is important to recognise that older people's health care needs are constrained by a lack of transportation to health care centres, being unaware of their entitlement and being geographically isolated from services because of a lack of transport. These factors coupled with the fact that most health care providers lack training and knowledge in geriatric care complicate the situation for older people (Stanley 2008).

5.2 Stigmatization of HIV/AIDS

Although many years have passed since the discovery of HIV/AIDS, people living with the virus continue to experience stigma. HIV stigma has been defined as "prejudice, discounting, discrediting and discrimination directed to people perceived to have AIDS or HIV, and the individuals, groups, and communities with which they are associated" (Herek, 1999a: 1107 in Keigher et al., 2004). The definition of stigma was further explicated by Green and Platt (1997 cited in Emlet, 2006: 782) who argue that "HIV stigma is a multidimensional construct which may be enacted or felt." They further claim that "enacted stigma refers to individually or collectively applied sanctions such as discrimination or prejudice, whereas felt stigma relates to feelings of shame or guilt." In Zambia, families that have been affected by HIV/AIDS and persons who are HIV positive experience enacted and felt stigma respectively; this attests to the universal nature of HIV stigma. Stigma is therefore a hindrance to the cultivation of social capital.

HIV leads people to face physical and social isolation which endanger the aspects of peoples' lives that enable them to participate in their communities. Stigma makes it difficult for

HIV positive persons to enjoy life with friends and relatives. In fact, HIV affected families tend to have little time to participate in various activities in their communities as they are preoccupied with survival. HIV and AIDS have generated fear, anxiety, and prejudice against people living with the virus. Being HIV positive also creates widespread stigma and discrimination in a population, adversely affecting both peoples' willingness to be tested for HIV and their adherence to antiretroviral therapy. Reducing stigma and discrimination is necessary in the control, management and prevention of HIV/AIDS (Chiwele, 2007). In Zambia, just like other countries in Africa, people who are HIV positive are subjected to stigmatisation and discrimination. "They are subjects of ridicule and are often perceived as hopeless and helpless people. Whatever they say or do, no matter how sensible, people would retort (this one is sick)... even the sympathy shown towards the HIV/AIDS people is superficial and not genuine. It is sympathy shown in the presence of the infected person. Immediately after that person leaves, they would be talking ill of them" (Mushingeh, 2002: 20).

In 2005, the Zambia Sexual Behaviour Survey (ZSBS) found that 97% of both men and women are aware of HIV and AIDS. Despite this awareness only 15% of the people surveyed had gone for voluntary counselling and testing (VCT). Most of the people avoid going for VCT because they fear the outcome of being tested coupled with the stigma and discrimination that would arise from a positive outcome (Chulu, 2007).

HIV stigmatization is a major challenge for people who are HIV positive as there is a perception that they are personally responsible for their condition. Even though there has been some decline in HIV related stigma in Zambia since the 1990s, felt and enacted stigma still pose challenges for HIV positive people and their families. Emlet (2006) confirms this, in his 2006 study which found that 50% of older adults reported they were ashamed of their illness, and 39%

indicated that they had lost friends because of being HIV positive. It is important to note that in Zambia, HIV stigma goes farther than just affecting people who are positive; it affects all those who are related to a person who is HIV positive. Although research has shown that grandmothers and their orphaned grandchildren are stigmatized on the basis of their children and parents respectively, there is still no clear and concise term for this kind of stigma, which might be referred to as 'stigma of association.' It is therefore clear that stigma prevents grandmothers and their families from building social capital and benefiting from social support.

The main method that HIV positive people use to manage the fear of enacted stigma is through protective silence. According to Emlet (2006) protective silence is simply the nondisclosure of one's sero-status to other people. In this case an HIV positive person deliberately decides not to inform others that he/she is positive as a way of stigma management. Protective silence is used mostly because HIV positive individuals do not know how their family, friends or potential sexual partners would react when told about their HIV status. Protective silence is, therefore, a major hindrance to the fight against AIDS because HIV positive people hide their status and continue having unprotected sex. However, it is difficult for HIV positive persons to deal with felt stigma; as they may continue blaming themselves for their condition and avoid seeking counsel. The following are some examples of enacted and felt stigma that HIV positive people have encountered in Zambia.

5.3 Examples of the Experiences of HIV/AIDS Affected and Infected People

In order to appreciate the challenges of grandparenting in the context of the AIDS epidemic, there is a need to consider some examples of grandmothers' experiences, such as that of Mrs. Mulenga, a grandmother and resident of Lusaka. This grandmother lost three sons and two daughters. Altogether they left her with the responsibility of caring for twelve grandchildren.

She had no education or training, could neither read nor write, and suffered from severe arthritic hips, yet she sold foodstuff by the roadside and managed to feed and clothe her grandchildren. It is clear from this illustration that Mrs Mulenga has refused to give up on life; she does not complain or indulge in self pity, although she is sad after losing her children and is overwhelmed by the stress and strain of caring for and trying to feed twelve grandchildren with her roadside business (Wane & Kavuma, 2001). It is obvious that Mrs Mulenga faces the challenges that are associated with role overload and role strain.

The story of a widow in Chipapa, near Lusaka is another clear illustration of how grandmothers are coping with life; this grandmother lost two sons-in-law and one daughter and is caring for one daughter who is HIV positive. She is also caring for twelve children of her daughters. She survives by working in a food-for-work program. However, she is unable to adequately support the family and keep her grandchildren in school. She is fearful of the impending death of her daughter and is also isolated; she has nobody to discuss her condition with. Her neighbours do not want to have anything to do with her (Baylies, 1996 in Baylies, 2002). The isolation that this grandmother is experiencing means that she is unable to establish social capital and enjoy the social support that comes with it.

Another example is of Don and Christine MacDonald from Scotland, now based in Lusaka, who have responded to such needs by initiating and running a project called 'Super Grans' Project. They are reaching out to grandmothers by funding school fees, providing food vouchers and providing medical care to the grandchildren. The aim of this project is to encourage family units to live together. The MacDonalds have also adopted 29 orphaned children aged between 9 and 21. They live on a farm called Old McDonalds in Lusaka, Zambia. They grow agricultural produce which they sell to sustain themselves and finance grandmothers in the

locality. However, the literature does not include details about when the project was started or how many grandmothers are being supported (Wane & Kavuma, 2001).

Most caregivers complain that HIV/AIDS infected persons are easily irritable, choosy in what to eat or indeed what items to use, such as utensils and cutlery. For instance, one caregiver from Minga, in Eastern province of Zambia, states that HIV/AIDS is a "particularly terrible disease because patients take so long to die and a caregiver ends up suffering." Another described how "months are spent looking after a patient, bathing and feeding them, as they linger on instead of dying quickly. It is a shame because people cannot be productive, just looking after you, when you brought it on yourself" (Baylies 2002: 367).

Njoka (2005, cited by De Witt, 2007: 2) shows us the agony of a mother who is HIV positive: "I wondered what would happen to my son after my death. I wondered how people would treat him once I had left for the new place.... I was thinking..... How is he going to face life without me?"   Research conducted by Goggin et al. (2001, cited in De Witt: 2007), also expressed similar concerns raised by dying mothers. They found that HIV positive mothers experience feelings of guilt and concern about the impact of HIV on their children, family, and caregivers in the future.

"Our parents both died in 1995," one young Zambian woman told UNICEF researchers. "When this happened, our relatives ran away from us. This surprised us because, being our relatives, we thought they would care for us.... Our parents had a big farm, but it was taken from us so we had nowhere to grow food. My young brothers and sisters became beggars; they would walk from house to house asking for food" (UNICEF, 2006). Begging in this sense is in line with the role strain model which states that individuals are compelled to assume deviant roles

due to structural roadblocks to meeting cultural ideals. A forty two year old HIV positive male in Lusaka had this to say:

"There is no help that comes from my friends. We do not get on well with my friend because they always laugh at me. They say we are sick and advise their family members not to interact with my family. When they laugh they make fun of us, 'look at the way that person has lost weight. They are so sick of AIDS: But we do not take it to heart because everyone is certainly affected with the epidemic, just ignore the people no matter what they say. Only God understands" (Chiwele et al. 2007: 45).

A Ndola male claims that, "when I go even to the bus stop, women start singing, 'that man is sick.' Stigma is still a very big problem. I always forgive these people because I think they are ignorant. It never angers me personally but there are those who take it even deeper" and, in Kapiri Mposhi, a woman had this to say, "Some people in the community treat households affected by HIV/AIDS with stigma and discrimination. It (HIV and AIDS) also robs one of self esteem. You just find that certain people start isolating themselves even from peers, church members and start living a closed life" (Chiwele et al. 2007: 45).

Margaret Njovu from Kitwe states: "I am 61 years old with seven children. Five of them have passed away. Ten grandchildren are in my care; two of them are HIV-positive and quite ill. Two of my own children are also critically ill. I started suffering in 1999; I am a woman who knew nothing about HIV/AIDS. My husband became sick with TB and in 2000, I became sick with TB. After eight months of TB treatment, I became sick again. I found out then that I was HIV-positive. My husband was a truck driver and had been sick for a long time. He was taking medication for a number of years, but he did not tell me of his illness. He said he didn't tell me because he thought I would divorce him, though he had deserted the home for six months

to be with another woman. In 2000, I started taking ARVs" (Landsberg-Lewis, 2007: 46).The challenges that families afflicted by AIDS continue to face are, in part, attributed to a lack of social support which is caused by stigma and discrimination. According to this perspective, people who are HIV positive need social support in order to cope with their condition. However, it is apparent from the above illustrations that in Zambia, people who are HIV positive, as well as their children and caregivers (grandmothers) are stigmatized and discriminated against. Subsequently, they are isolated and lack social support which is necessary for the family to cope with the impact of HIV/AIDS. From these illustrations, it is evident that most of the people who are adversely affected by HIV/AIDS are women who have neither power nor resources to have their situation recognized by government and organizations that can help them. They also lack social capital to help them mitigate the impact of AIDS on their families and are constrained by role conflict due to the many tasks they perform. They are therefore, not able to enjoy a good quality life.

5.4 Coping Strategies of HIV/AIDS Affected Families

The coping strategies adopted by families affected by HIV involve the use of savings or sale of assets, and other households providing assistance. If savings are available these are used and taking on debts is usually the first option for families struggling with medical treatment or funerals. When debts mount, these families sell assets such as bicycles, livestock, and even land. Once families lose their assets, chances of recovering are almost zero. Assistance from other households is unsustainable.

As indicated earlier, Zambia does not have a well developed social security system; as a result the extended family has been the only safety net on which families in need depend. However, the growing number of children orphaned by AIDS is overloading the capacity of the

extended family. This is evidenced by the emergence of households headed by grandmothers, women, and children, where children as young as eight years are taking on the role of household heads and are providing care for other children. The epidemic coupled with poverty has curtailed the capacity of families to sustain them.

When a family member becomes sick, the role of women as caregivers, income earners, and housekeepers becomes even more critical. They are often compelled to step into roles which were traditionally for men. For instance, in Zimbabwe, women are moving into the carpentry industry. As a result, women have less time to take part in household chores (AVERT, 2009). This is because grandmothers spend most of their time caring for their dependants; as a result they have no time to spend with their peers. They, therefore, become isolated because they have no time to devote to social networks that need to be promoted to prevent isolation and loneliness (AVERT, 2009).

5.5. Zambia's Response to the HIV/AIDS Epidemic

As a response to the first case of AIDS in 1984, Zambia established the National HIV/AIDS prevention and control program, which initiated short and medium term strategies to deal with the problem. Also, in 1999, the National HIV and AIDS Council (NAC) were formed. NAC developed a national HIV/AIDS/STI/TB plan which resulted in the formation of the HIV and AIDS Policy (Chiwele: 2007). Subsequently, all sectors, such as the public, private, nongovernmental organizations, religious, and civil society, have included HIV/AIDS in all their training programs. In order to strengthen the work of NAC, in 2002, the Zambian parliament passed the NAC ACT which also included HIV/AIDS in all aspects of training, leading to the creation of a committee at cabinet level, as well as including strategies for combating the pandemic in the Transitional National Development Plan (TNDP) and the Fifth National

Development Plan (FNDP). Task forces have been formed at district and provincial levels. Additional measures to address the epidemic include "expansion of voluntary counselling and testing and prevention of mother to child transmission of HIV programmes to district levels, support to home based care programmes, incorporation of nutritional programmes as part of care and support for the people living with HIV and AIDS and the provision of condoms and drugs for sexually transmitted infections" (Chiwele et al, 2007: 32). Other initiatives involve specific groups such as youths, truckers, farmers, sex workers, and people living with HIV and AIDS, and those in formal employment. However, there are no programs targeted at grandmothers basically because they are a vulnerable group of women who lack the power to rally governments to recognize their plight.

One of the major responses to the HIV/AIDS epidemic that the government of Zambia embarked on was the program called Zambia National Response to HIV/AIDS (ZANARA), which operated under the Community Response to HIV/AIDS (CRAIDS), and was initiated in 2002 with a grant of $42 million from the World Bank's International Development Agency. A total of 1080 community projects were funded. CRAIDS' fight against AIDS was through financial support to institutions such as, community organisations, the National AIDS Council and Secretariat; 21 government ministries to streamline HIV/AIDS activities at places of work, and to the Ministry of health for program administration and implementation (Ministry of Health, UNAIDS, & UNDP, 2008).

ZANARA completed its work in 2008 and was said to be a major success, as it met all its objectives. This is confirmed by the results of the 2007 Demographic and Health Survey Report (DHSR), which indicates that the country had experienced a reduction in HIV prevalence among antenatal women younger than 20 years old from 12.6% in 2002 to 8.7% by 2007. The national

adult HIV prevalence also declined from 16% in 2002 to 14.3% during the same period. These results are attributed to HIV sensitisation programs, which lead to an increase in condom use. Among males aged 15 to 24 condom use at last sex with a non-regular sexual partner increased from 30% in 2003 to 45% in 2007 and among females in the same age group condom use at last sex with a non-regular sexual partner increased from 17% to 29% during the same period (Ministry of Health, UNAIDS, UNDP 2008).

However, even in this elaborate program to combat HIV/AIDS, grandmothers are not targeted, although many other groups are considered. Notwithstanding this, a group of grandmothers and widows who care for AIDS orphans organised themselves and established the Kilelabanda (Kilelabanda means looking after the vulnerable) project in Solwezi, North-Western Province, about 500km from Lusaka. They sought support from Kansanshi Mines which built a dormitory for them which they use for a school feeding program for their grandchildren and other vulnerable children. Kilelabanda also sought financial support from ZANARA through CRAIDS who responded by providing funds for the rehabilitation of an old abandoned government building that grandmothers have turned into the Makole Community School. The Makole Community School and the Kilelabanda orphanage have gone a long way in alleviating challenges faced by grandmothers in HIV/AIDS afflicted families (Ministry of Health, UNAIDS, & UNDP, 2008).

Further, the government of Zambia in conjunction with the community and NGOs have continued to fight the HIV epidemic. For example, in order to make sure that orphans stay in school, the community has responded in three different ways. First, they influence the local school management committees to exempt orphans from paying school fees. However, this method tends to work against the financial base of the school. As an illustration, in Kitwe town,

at Chimwemwe Primary School, with a total population of 1500 pupils, 400 orphans and vulnerable children were excluded from paying school fees which resulted in depleting the school finances by almost a third. The second strategy to keep children in school involves the community organising fund raising ventures and using the funds to offer bursaries to orphans. However, communities are unable to raise enough funds due to lack of start up capital, management skills, and marketing opportunities to run the projects. The third response is the introduction of community schools or open schools, which do not require uniforms or fees from pupils. All teachers volunteer their time and the curriculum is compressed from six years to only three. The open schools were so popular that they rapidly increased in number. However, open schools have not been successful because they compromise the quality of education. This is because teachers volunteer, and as a result they are not committed and motivated to work; it is common for them to miss classes on flimsy grounds (Fleshman, 2001).

Since the discovery of AIDS in the 1980s, the response to tackle the epidemic has been swift in Zambia. Hundreds of community based organisations, NGOS, and homecare projects have been formed to care for the sick and provide support and counselling for orphans and their families. Unfortunately, most of the programs are uncoordinated and merely duplicate the work being done by other organisations. World Vision Zambia is the lead organisation in one coordinated program called RAPIDS (Reaching HIV-Affected People with Integrated Development and Support). The RAPIDS group of organisations is funded by the United States President's Emergency Plan for HIV and AIDS (USPEPHA). Other members of RAPIDS are CARE, Catholic Relief Services, Africare, Expanded Church Response, and the Salvation Army. The project has been given US$57 million for care and support of orphans and vulnerable children (OVC) and people living with HIV and AIDS. This is a multi-faceted project that covers

53 districts in Zambia and includes farmers, widows and orphans who receive support such as seeds, tools, training in improved farming techniques, the encouragement of HIV testing and adherence to medical regimes for AIDS treatment, and helping children with school fees. It is important to recognise that RAPIDS is not exclusive to the fight against AIDS; it also includes poverty and drought. In all these programs, none is targeted at grandmothers caring for AIDS orphans. However, grandmothers do receive indirect support through the orphans and vulnerable children they care for though it is not adequate (Peterson, 2007).

It is important to recognise that Zambia was one of the first countries to recognise the weakness of established health institutions in dealing with long term care for people with HIV and initiated a home based care program. Other initiatives developed in Zambia include "public declaration of HIV positive people in order to reduce stigma. Some of these initiatives are now being practised in a number of third world countries" (Chiwele, 2007: 1). Public declaration means that a person who is HIV positive comes out in the open to inform others of their HIV status.

Zambia's ability to adequately respond to the AIDS epidemic is constrained by many factors including the poor state of the economy and lack of trained manpower. For example, Table 3 indicates that the population of Zambia in 2007 was 12,160,516. In the same year, there were 646 doctors and 9,000 nurses in Zambia. This means that for each doctor and nurse, there were 18,824 and 1,351 patients respectively. Even if people do not get sick at the same time, these ratios are extremely high. It is therefore likely that many people, especially women, the poor and lower class, in rural areas, may not have access to either a doctor or a nurse. Meanwhile, the rich are not affected by this lack of health workers because they can afford to pay for private services. This may also explain why grandmothers are required to take care of

their loved ones who are admitted to hospital because of a shortage of medical staff due to poor funding of public institutions. This situation is very stressful for grandmothers. The conflict perspective would attribute this state of affairs to the exploitation of the powerless by the powerful.

According to Table 3, the number of doctors and nurses and other health personnel has been stagnant from 2005 to 2007, yet every year health personnel are graduating from colleges and universities (Chiwele et al, 2007). There is no explanation for this in the 2007 Zambia Healthy Demographic Report (ZHDR). It may be assumed that health personnel have continued to leave the country for greener pastures abroad. Table 3 also indicates that, during this same time period, there was an increase in the overall HIV adult prevalence rate, and the number of deaths attributed to AIDS. In 2005, 1,200,000 people were HIV positive and 95,373 died from AIDS; by 2007, 1,482,228 were HIV positive and 97,494 had died from the epidemic. On a positive note, there is some evidence that the incidence rate is decreasing (e.g., general prevalence dropped from16% in 2002 to 14% in 2007).

Table 3
Demographic Indicators

Year	2005	2006	2007
Total population	11,441,461	11,798,678	12,160,516
Age 15-49	5,842,187	6,033,674	6,227,228
Adult HIV Population	1,200,000	1,300,000	1,482,228
Adult Deaths	95,373	96,202	97,494
Paediatric HIV Deaths	6,000	7,000	8,283
General Prevalence	16% (2002)		14%

Adult Prevalence	13.9%	13.5%	13.1%
Number of Orphans & Vulnerable Children	1,197,867	1,241,368	1,291,079
Number of AIDS Orphans	710,000		845,546
Health Indicators			
Number of Physicians (estimates)	646	646	646
Number of Nurses	9,000	9,000	9,000
Other Health workers	13,000	13,000	13,000
Number of Hospitals	97	97	97
Number of Health Centers	1,210	1,210	1,210

Zambia Country Report*:* (2006-2007: pg IV)

5.6 Home Based Care

Most of the countries in sub-Saharan Africa have responded to the HIV epidemic by promoting home based care (HBC) programs. Home based care is aimed at involving the family in caring for a person who is HIV positive. The person is cared for by his or her family with the support of professional social welfare officers and community volunteers. It is hoped that the program would meet the material, emotional, and economic needs of persons with HIV and AIDS.

It has been observed in Africa and Zambia in particular that caregiving has a gender dimension. This is because mothers have been seen as more likely to provide care than fathers. As indicated earlier, this is largely attributed to the Zambian culture where females are more involved in caring than males. Also, in most cases women tend to outlive men. This is supported by Akinsola (1999 in Ferreira 2004*)* who claims that in African culture the responsibility of caring for the sick , the old, and the disadvantaged is that of women, and to some extent girls.

However, Ferreira (2004) maintains that home based care is one way in which governments transfer responsibilities for caring for the sick to families, since the government is unable to fully support people with HIV and AIDS due to a lack of capacity, financial, and material resources. Regardless of the reasons why governments promote home based care, with adequate support and funding from government, home based care programs would go a long way in helping to alleviate the challenges being faced by HIV/AIDS afflicted families. In sub-Saharan Africa, only three countries: Botswana, Namibia, and South Africa have comprehensive social protection measures. This may explain why home based care is preferred in this region (Ferreira, 2004).

Worldwide, before governments, charitable or other welfare agencies and sectors provided care, help, and money to people who were ill, or in need of assistance, families and communities were expected to play these roles (Evans & Becker 2009). The "significance of the family as both an institution of welfare and for care giving exists almost irrespective of the country's familial, social and socio-political structures" (Jani-Le Bris, 1993 in Evans & Becker 2009: 1). Universally the family is a very important institution for taking care of and socializing children because it lays the foundation for other socializing agents such as the school, church and community at large.

An analysis of formal institutional care and support for grandmothers caring for HIV positive children indicates that in Zambia, there is no formal institutional support for persons afflicted by HIV/AIDS. Most of the support and care is informal (home based care) and is provided by grandparents, in particular grandmothers who care for their adult children as well as orphaned grandchildren. Grandmothers provide personal caregiving, such as performing personal hygiene, administering medicines, cleaning wounds, feeding, and provision of transportation (Knodel 2005).

Nevertheless, much of the support that grandmothers receive comes from self help groups which are organised and run by grandmothers themselves. Such groups are uncoordinated and lack a central support mechanism. Activities that such groups provide include caregiving assistance or advice, companionship or support. Sometimes these groups sponsor income generating activities. In some cases formal support is provided by NGO's, also, the government provides indirect support to grandmothers. Such support is given to children through social welfare; however, it is inadequate.

Since there is no formal institutional support to help women cope with their caring responsibilities, women have embarked on projects to tackle the consequences of HIV/AIDS on their households. An example is that of a "women's" group in Chingola, Zambia. One peculiar thing about this group is that it is comprised of women aged between 36 and 45. The group was initially formed to supplement their families' incomes. However, later they discovered that in their community, HIV/AIDS had inflicted suffering on most of the families. The group was helped and trained as peer educators by the Copperbelt Health Education Project. Currently, the group goes around the community counselling families that are affected by HIV and educating them on the dangers of the epidemic (Baylies 2002).

In conclusion, formal institutional care for people with HIV/AIDS is lacking. Hospitals are congested and there is a shortage of social workers who are supposed to assist informal caregivers. With enough funding and support, home based care could help to improve the situation. In fact, home based care is much cheaper than keeping people who are chronically ill in hospital for prolonged periods. However, the biggest challenge facing home based care in Zambia is that the major players, grandmothers, are still not included in HIV/AIDS programs.

It is worth noting that as far as the conflict perspective is concerned, home based care programs are intended for the poor and powerless classes. This is in view of the fact that the rich are able to pay for private services, and therefore do not face similar challenges. Plus, home based care is cheaper and it relieves society of the responsibility for providing more formal institutional care.

5.7 The Stephen Lewis Foundation

Notwithstanding the above, Stephen Lewis who was the United Nations Secretary General's Special Envoy for HIV/AIDS in Africa from 2001 until 2006, noticed the suffering that grandmothers were experiencing because of HIV/AIDS during his travels in Africa and decided to help them. In 2003 he formed the Stephen Lewis Foundation (SLF), and in 2006 he launched the Grandmothers to Grandmothers Campaign to address the growing needs and pressures facing grandmothers in Africa who are dealing with the consequences of HIV/AIDS. The SLF is the only International Non Governmental Organisation (INGO) world-wide whose objective is to raise funds to help grandmothers caring for AIDS orphans in Africa, in particular sub-Saharan Africa, which is the worst affected region in the world. The funds that are raised are used to provide for grandmothers' immediate needs – food, transportation, medical care, housing, as well as the needs of the orphans in their care, such as school fees, uniforms, and other supplies. The foundation also helps people living with HIV/AIDS by providing nutritional support, home based care, prevention workshops and assistance in accessing treatment. In addition, the SLF provides small scale loans as capital to help the grandmothers venture into income generating activities. Most of the grandmothers sell items such as paraffin, sugar, salt, and cooking oil on the streets or in small stalls. Since its inception the SLF has supported 142 projects in sub-Saharan Africa (Lewis, 2008).

As indicated earlier, the foundation funds home based care workers in Africa. Most home based care workers are women; many of them are HIV positive and care for orphans and sick family members. Lewis (2008) states that grandmothers single-handedly care for millions of AIDS orphans and in some cases they look after as many as 10 to 15 in their homes. They also care for their HIV positive children- bathing, feeding, providing comfort and counselling.

Furthermore, in a film entitled Grandmothers; The Unsung Heroes of Africa, by Liz Marshall, Stephen Lewis makes a point that grandmothers have emerged as saviours of the African continent, as they tend to millions of orphaned children. Nonetheless, "One of the fascinating aspects of this, is that there is no data on the grandmothers; nobody knows the number of grandmothers; nobody has chronicled exactly what they do; nobody has any statistical evidence about the lives they lead and yet they show such courage in the face of such odds" (Lewis: 2008).

The SLF, as the only organization that has programs targeted at alleviating the challenges that grandmothers are facing because of HIV/AIDS, supports grandmothers in Zambia. For instance, in 2004, the SLF financed a grandmothers' project in Kabwe, Zambia, called Busy Bees. This group comprises grandmothers who are infected or affected by HIV/AIDS and most of them care for HIV/AIDS orphans.

The grant that the SLF provided enabled the women to; receive training in advanced sewing skills, purchase sewing and knitting machines, purchase materials for sewing, get trained in agriculture and purchase equipment and fertilizer to use in their vegetable gardens. As a result, the women have produced various types of crafts, including knitted sweaters to beaded necklaces; from ornate dolls to embroidered food coverings. All these products are sold in the local market in Kabwe. The finances they raise from this project are shared and used to feed,

clothe, and shelter their families, and some of the income is used to pay for the education and health needs of their grandchildren. Also, these grandmothers are a source of encouragement and inspiration to their colleagues. As such, they meet daily under a tree to share their worries, strengths, skills, and talents (SLF Newsletter 2009).

However, there is no information in the literature indicating the amount of money the SLF provided to the grandmothers in Kabwe. The SLF headquarters in Toronto, Canada was contacted to provide details on this particular project and other projects they are involved in, but they declined to do so, claiming that they receive too many requests for information which would be too expensive to fulfill.

On another note, in August 2006 the SLF organised an international AIDS conference for grandmothers which was attended by 100 African grandmothers from 11 sub-Saharan African countries and 200 Canadian grandmothers. This was the first international forum where African grandmothers met and discussed their plight with Canadian grandmothers who support the SLF. The major issue to come out of this conference was the challenge and fears that the grandmothers have about sex and sexuality. It is a challenge for them to educate their grandchildren on the dangers of AIDS because they lack knowledge. It was also clear that most of the grandmothers were not targeted for assistance and counselling for HIV. As a result they contracted AIDS while tending to their dying children because they were unaware of precautionary measures. At the end of the conference the grandmothers' needs were outlined in the Toronto Statement as:

> "In the short term, we do not need a great deal, but we do need enough: enough to safeguard the health of our grandchildren and ourselves; enough to put food in their mouths, roofs over their heads and clothes on their backs; enough to place them in school and keep them there long enough to secure their futures. For ourselves, we

need training, because the skills we learned while raising our children did not prepare us for parenting grandchildren who are bereaved, impoverished, confused and extremely vulnerable. We need the assurance that when help is sent, it goes beyond the cities and reaches the villages where we live. In the long term, we need security. We need regular incomes and economic independence in order to erase forever our constant worry about how or whether our families will survive. We grandmothers deserve hope. Our children like all children, deserve a future. We will not raise children for the grave" (Landsber*g*-Lewis, 2007: 11).

Furthermore, in 2010 the first international Grandmothers' Gathering on the continent of Africa took place in Swaziland. It was attended by 500 grandmothers from 14 sub-Saharan African countries. Grandmothers shared their experiences and knowledge on how to surmount the challenges that HIV/AIDS has inflicted on their families. At the end of the conference they enumerated the following demands on the international community and their respective governments:

1. "We demand the economic independence to support our families, to provide nutritious food; decent housing; access to ongoing quality education for our grandchildren; and a richer quality of life for us all.

2. Grandmothers must have meaningful support in the form of pensions and social security, and

3. Laws must be passed and implemented ensuring the safety and rights of grandmothers and their grandchildren" (The SLF: 2010: 2).

The work that the SLF is doing should be greatly appreciated; however, as the only institution that provides assistance to grandmothers caring for AIDS orphans, it is overwhelmed

and unable to meet all the needs of grandmothers. As an illustration, by 2006 the SLF had raised $11 million in Canada for projects in Africa. Meanwhile, according to statistics there are about 12,000,000 orphans in sub-Saharan Africa. Assuming that every orphan was to receive help (excluding grandmothers who care for them), it means that each would be supported with an equivalent of 92 cents. By any standards, this amount is inadequate. Nevertheless, the SLF should be commended and supported for the work that it is doing; without the SLF the impact of HIV/AIDS on grandmother headed families in sub-Saharan Africa would be too ghastly to contemplate. In light of a lack of government programs targeted at helping grandmothers, it is conceivable that the challenge of grandparenting in the HIV affected families in Zambia may take a long time to address.

5.8 Contributions of the Study

Most of the research on HIV/AIDS has focused on epidemiological or biomedical aspects of the epidemic. Very few studies have investigated the social impact on society and on the family in particular although the epidemic has had an extremely negative impact on both individuals and society at large. This research highlights the social impact of the epidemic on the family, especially on grandmothers caring for AIDS orphans and the review of the available research using a sociological term is a significant contribution.

The three perspectives of conflict theory, social capital and role conflict were used to situate the research questions addressed in this study in a social context, and to provide a comprehensive theoretical framework for analyzing and interpreting the findings at the macro and micro levels. For instance, the government of Zambia has encouraged families to provide care to terminally ill persons through the promotion of home based care programs instead of using the formal health care system to look after those who are HIV positive. The government

has been able to do this because the poor people, in particular grandmothers who are caregivers have neither influence nor resources to compel the government to support them. This plan effectively reduces government intervention and responsibility for the high social costs of the HIV/AIDS epidemic.

According to the conflict perspective, the government has also absolved itself of the responsibility for providing care for orphans because they are a poor, powerless class. Since the government is aware of the problems of orphanhood, it seems they have deliberately encouraged the extended family system to care for them, although the extended family lacks the capacity to do so. As a result, children are compelled to work when they are supposed to be in school. Consequently, these children have no opportunity to move upwards on the social stratification ladder. This results in the perpetuation of inequality, as the children from the upper classes continue to pursue their education and maintain their positions on the social stratification hierarchy. Children from poor families may continue to lack opportunities to further their education, thereby being confined to manual, low paying jobs. Otherwise, they will be roaming the streets while the better paying jobs remain in the hands of the upper classes. The conflict perspective argues that the perpetuation of this pattern of employment reinforces social and economic inequalities in Zambia.

Further, the inequalities in education and employment opportunities have also affected the health sector. It is clear that the poor do not use the services of better medical institutions because they lack financial resources to pay for them. They are therefore confined to government health care services that lack manpower, equipment and drugs and consequently are unable to handle the impact of the AIDS epidemic on their families. Meanwhile, the rich are able to surmount the impact of HIV/AIDS because they have access to better medical facilities since

they have the financial resources to pay for them. The conflict perspective helps us to understand the consequences of HIV/AIDS on society's poorest families.

Furthermore, the premature death of parents due to HIV/AIDS has lead to changes in the structure and composition of the family. Families are now headed by grandmothers, women, and children. In their new positions as heads of households they are expected to play various conflicting roles, which are a recipe for role overload and role strain. For instance, as a head of a household a grandmother is expected to play the role of a father, mother and indeed that of a grandmother to her grandchildren. Meanwhile, as heads of households' older children are also expected to play similar roles as a grandmother. It is clear why they face role overload and role strain. In sum, the role conflict perspective helps us to understand how the HIV/AIDS epidemic has permanently changed the family structure.

The changes that have taken place in the family have affected the community as a whole. Heads of households such as grandmothers and children are so overloaded with responsibilities, including leading, teaching, and assisting their grandchildren and siblings respectively that they are unable to go out and interact with other people in the community to establish social capital. Social capital is an investment; as such grandmothers and children heading households may not be able to find time to attend community functions such as worship or volunteering, which are the primary sources of social capital; hence they are unable to benefit from social support. Consequently, they continue to face challenges in their families which could be resolved by social capital, and they are unable to effectively mobilise to bring their concerns to government because of their lack of resources.

Finally, the three perspectives utilised in this study enabled us to understand and interpret the social impact of the epidemic and the challenges of grandparenting in HIV/AIDS afflicted

families. The conflict perspective helped to analyse these challenges at both macro and micro levels. It focused attention on the influence of social structures on grandmothers' positions and roles in their communities and society in general, and their ability to provide care for AIDS orphans. Role conflict emphasized the interpersonal dimensions of these challenges and the importance of a micro level analysis. Meanwhile, social capital provided a conceptual link between the conflict perspective and role conflict. It helped to show how grandmothers' lack of interaction in their communities has resulted in their inability to benefit from social capital and to lessen role conflict. From a conflict perspective, it may be concluded that when grandmothers become class conscious they may be able to reduce the impact of the epidemic on their families. This is because with strong social capital they may be able to form coalitions and have their concerns raised in the HIV/AIDS dominant social discourse, thereby influencing the ruling elite to formulate policies and programs to support them.

This study has therefore given us an opportunity to unearth and understand the challenges that grandmothers caring for their AIDS orphans are facing and consequently to offer solutions. The increasing number of HIV/AIDS orphans in Zambia will have far reaching consequences for many years. Considering that Zambia is a developing country with dilapidated health facilities and a shortage of trained health personnel, it is most likely that on its own, the country may not have the capacity to resolve this problem. It is necessary for the international community to come to the aid of Zambia, since it is clear that given the magnitude and complexity of the problem, the combined effects of HIV/AIDS and poverty on families (particularly grandmothers and orphaned children) need to be tackled concomitantly.

With the support of the international community, a variety of programs should be implemented in order to assist grandmothers and their orphaned grandchildren. Such programs

should include formulation of policies and programs targeted at helping grandmothers balance varying and conflicting roles, as well as strengthening communities and family support networks. It is also necessary to include older adults, especially women, in current HIV/AIDS programs, such as education, health campaigns, promotion of condom use, and provision of antiretroviral drugs. Formulation of anti-poverty and/or income redistribution measures would enhance the capacity of grandmothers. This is in view of the fact that this research concluded that the challenges faced by grandmothers are, at least in part, due to their exclusion from HIV/AIDS programs and policies. Lastly, the government should encourage families to adopt orphans and support such families morally and with resources such as the provision of free education and health services. Also, the government should provide resources for volunteer caregivers and faith based organisations in order to motivate them and strengthen their capabilities.

The results of this study not only contribute to academic literature, but have policy implications as well. The government of Zambia may use the recommendations of this study to formulate policies and programs targeted at helping grandmothers alleviate their suffering and provide better care for their orphaned grandchildren. For example, one possibility might be to give grandmothers grants through micro-financing to enable them to start small scale businesses. Results of this study may also be replicated in other countries in sub-Saharan Africa, Asia and worldwide where the situation is similar to that in Zambia. HIV has affected the entire world as Draimin and Reich (2005: 213) argue that "despite cultural differences between the United States and other areas affected by the global HIV epidemic, there are also similarities. Parents grieve the deaths of children; grandmothers take on the care of their grandchildren; children's lives are irrevocably altered by a parent's death." The impact of HIV/AIDS on the family is not peculiar

to Zambia; it is universal and, as such knowledge gained from this study could be used elsewhere.

5.9 Limitations of the Study

This type of secondary research has a number of advantages. First, the study is inexpensive because the data are easily available. Second, the study does not involve direct contact with human subjects; hence there were no ethical issues. Third, this method allowed for the use of large amounts of data and also the latest information on the topic.

However, it is important to also acknowledge that secondary research has weaknesses. As such, the major challenge this study encountered was that although the available data addressed the research questions and objectives, there were gaps in the information because the data were collected for different purposes. For instance, there is no data to explain why the government of Zambia does not have any targeted support for grandmothers, yet it has been acknowledged that they play an important role in caring for orphans. The data is also silent on the role of grandfathers. Available data indicate that the HIV rate in Zambia is higher among the more educated. The research literature does not provide a reason for this contradiction, since it is known that knowledge is supposed to help people protect themselves from the virus. This research has therefore not been able to address these concerns. Further, in case the original researcher had made errors, these could not be detected and corrected (Singleton & Straits, 2005).

In addition, it is possible that the authors of journal articles that were used as sources of data may have included their own opinions in the publications (reflecting their personal views of HIV/AIDS). In order to address this bias, all the literature obtained from individuals or groups of individuals was compared with literature from known international organization such as the

United Nations, UNICEF, WHO and the Joint United Nations Program on AIDS Reports. In addition, the researcher was unable to get first hand information because it was not possible to talk to the grandmothers. It is important to keep these types of issues in mind when interpreting the research evidence reviewed.

CHAPTER SIX – CONCLUDING DISCUSSION

<u>6.1 Conclusions</u>

It has generally been agreed by all stakeholders, including the Government of Zambia, local NGOs such as Child in Distress (CID), and International Non Government Organisations (INGOS) such as the Stephen Lewis Foundation (SLF), that grandmothers have been adversely affected by HIV/AIDS. Although they are caring for about 40 to 50% of the orphans, there are no government programs directly targeted at assisting them. The situation has been aggravated by a lack of information on the status of grandmothers caring for AIDS orphans. So far the literature has not shown the role that grandfathers play in caring for HIV/AIDS orphans. It can only be concluded that it is due to the patriarchal nature of the Zambian society and/or because of the way society is organized around gender roles regarding child rearing.

The experiences of grandmothers are worsened by the fact that for some time now, the impact that HIV/AIDS has had on older adults has not been included in national policy and programs. It is therefore necessary for the Zambian government to address this issue by coming up with a framework that will, for example, encourage the involvement of older adults and grandmothers in HIV/AIDS related programs. In addition, the government should raise awareness of how HIV/AIDS affects grandparents, increase grandparents' access to HIV/AIDS education, support home based care programs that meet older people's needs as caregivers, and provide resources and psychological support to help them surmount the challenges that HIV/AIDS has inflicted on them.

This study has shown the devastating effect that HIV/AIDS is having in sub-Saharan Africa and in Zambia in particular. The overall impact of HIV/AIDS in Zambia is yet to be known. However, many lives have so far been lost, and this has stretched the extended family

system to an extent that it is unable to cope with its responsibilities. As a result, child, female, and grandmother headed families are now a common feature. However, the challenges that these families are facing are not fully comprehended due to a paucity of studies on the subject. Without any targeted support from the government or the community, for example, psycho-social counselling and provision of income, it is apparent that these families cannot establish social capital and benefit from it.

The challenges that HIV/AIDS have brought to Zambia have far reaching implications whose consequences cannot easily be determined. There is therefore a need for concerted efforts by all stakeholders to arrest the situation. With no cure in sight, it is imperative that efforts to address this epidemic are enhanced as soon as possible. Since HIV/AIDS is killing people in the prime of their working lives, there is a consensus that it has the effect of sharply reducing the labour force and destroying inter-generational socio-cultural capital formation (Poku 2005). Social networks are a valuable asset as interaction enables people to build communities, and support each other. When parents are HIV positive and eventually die, their children are stigmatized and discriminated against, and eventually they lose social capital, and are unable to obtain social support which is a necessity for life.

It is clear from this study that nearly all families and communities in Zambia have been directly or indirectly affected by HIV/AIDS. Nearly everyone knows somebody who is either HIV positive or has a relative who is HIV positive, or indeed who has died from the pandemic. The major consequence of HIV/AIDS is the growing burden of orphans and the challenge that it places on grandmothers. For instance, grandmothers have not been prepared or trained to care for children who have been traumatized by the death of their parents, stigmatized through association with HIV/AIDS and left in abject poverty by the loss of their parents. The family has

the responsibility of caring for and socialising children and is facing unprecedented challenges. This has the potential to slow down the country's economic development and curtail the provision of social services such as education and health care. Although a lot of other research on HIV/AIDS has been conducted, this area is under researched.

It is clear from this study that HIV/AIDS has continued to negatively affect the family, especially grandmothers and their orphaned grandchildren in Zambia. For instance, the traditional role of grandmothers which was to teach their grandchildren values and norms has changed. Grandmothers are now breadwinners, and heads of families. The plight of grandmothers has been compounded by the fact that they are expected to play multiple roles such as mother, father, and indeed grandmother to their orphaned grandchildren, which leads to role overload and role strain. It is also now a common feature for children to be breadwinners and heads of families and consequently be subjected to role overload and role strain.

Further, HIV/AIDS has eroded the values and importance of the extended family system. Uncles, aunties and cousins are slowly disappearing from the extended family due to AIDS mortality, and the nuclear family has become prominent leaving limited resources for orphaned children. Street children and child labour have become part of the Zambian society which was not the case before the advent of HIV/AIDS. Discussions of sex and condom use which were taboo in the past are now openly talked about on television and radio in Zambia.

In order to address this situation, the government of Zambia, with the help of the international community, needs to provide resources to grandmothers and their orphaned grandchildren so that the children who are roaming the streets may be able to go back to school. If nothing is done to address this problem, the plight of grandmothers and their orphaned grandchildren will be aggravated. It is also most likely that the army of young uneducated and

unemployed people will continue to increase and pose a major challenge in the country in the next few years which may lead to social instability.

Finally, so far, a review of literature has not disclosed any prior studies on grandparenting and/or HIV/AIDS that have utilized any of the theories employed in this research, although many studies have been conducted on this topic and have come up with similar results. For instance, Fuller-Thomson (2005), in his study of Canadian grandparents as caregivers found results consistent with this study, for example, that grandmothers and not grandfathers raise grandchildren in skipped generation households. Also, grandmothers experience role overload and role strain mainly because they lack social support. In addition, in her study in Montreal on "full time grandparent caregivers-their feelings and experiences," Susan Baranyai (2002) concluded that grandparent caregivers tend to experience role conflict, to be socially isolated and to lack social capital.

Furthermore, John Knodel and Chanpen Saengtienchai (2005) in their study of older aged parents in Thailand concluded that "although older adults, especially grandmothers, play an important role as caregivers of HIV/AIDS children as well as care for their orphaned grandchildren, their work is unrecognised. As a result, they are not supported; consequently, they suffer adverse effects to their physical, emotional and economic wellbeing" (Knodel, 2005: 692). This study brought to our attention the fact that grandmothers are discriminated against on the basis of their gender, age, and class, and as a result they are unable to surmount the challenges that HIV/AIDS has inflicted on their families due to a lack of social capital.

6.2 Recommendations

As long as society continues to exclude older adults from HIV prevention programs, more adults will become HIV positive and this is likely to have a negative impact on Zambian

society as a whole. It is therefore necessary to urgently formulate a framework that will target the education of older adults on the dangers of HIV/AIDS.

Since grandmother caregivers have no influence the work they provide is unrecognised, which is why there are no targeted programs for them. As a result, they lack support and consequently suffer emotionally, physically and economically. Knodel (2005: 692) claims that "the continuing lack of recognition of the intensive involvement of older persons as mothers and fathers of persons with HIV and AIDS in the global AIDS epidemic is most unfortunate and urgently needs to be remedied." In order to address the challenges of grandparenting in HIV/AIDS affected families, there is a need for more research to understand the implication of HIV/AIDS on orphans' lives and their caregivers (grandmothers).

For the government of Zambia to increase institutional care in order to deal with the situation is almost impossible because it would be too expensive. It would also be detrimental to the children who need to live in a family environment in order to be properly socialized. The alternative to institutionalization is to allow children to live in their homes, but recruit community members to visit the orphans where they live with foster parents such as grandmothers or other relatives, or indeed in child headed households (AVERT, 2009).

African women and Zambian women in particular, are expected to be submissive to their husbands when they get married. In part, this is because husbands pay lobola (bride price), which clearly bolsters the idea of the husband's superiority in the relationship. It is assumed that since the husband has paid for his wife, she has to show appreciation by giving him what rightly is his-sex (Jesuit Center for Theological Reflection Quarterly Bulletin, 2010). It is therefore difficult for most women to negotiate condom use with their partners because of cultural norms that teach them not to deny conjugal rights to their partners. Even though they could use condoms to

protect themselves from sexually transmitted infections, including HIV/AIDS, they are not able to so. This may also be because of the belief that use of a condom may interfere with intimacy, as well as the fear that it may mean a lack of trust of their partner. In any case, most Zambian men feel that the use of a condom reduces sensation during sex (Kiegher, et al., 2004).

These factors contribute to the reluctance of women to deny sex to their husbands and makes women even more vulnerable to HIV/AIDS (Ministry of Health- Zambia 1997 in Baylies 2002). Furthermore, Chulu, (2007: 20) contends that "poverty is one of the factors driving the spread of HIV because it sets the scene for greater susceptibility to infections." It is therefore important to recognize that addressing gender issues, as well as poverty and class disparities may enhance the fight against HIV.

This study has shown that the SLF is doing commendable work; however, their work in Zambia may have encouraged the government to turn a blind eye to the plight of grandmothers. It may be necessary for the SLF to get government involved in assisting grandmothers by requesting the government, for example, match its budget by 50%. That is, for every two dollars the SLF spends on grandmothers, the government should be asked to contribute one dollar. This would compel government to respond positively.

From the conflict perspective, it is clear that grandmothers have been excluded from HIV/AIDS programs because they are women who have no resources, power or influence. In order for the government of Zambia to respond to the needs of grandmothers, they need to become class conscious, organise themselves and form a body (NGO) that will be able to campaign for support from other NGOs and to lobby government. Once they have organized themselves, they may be able to gain greater social support which will enhance their social capital and consequently the quality of their lives.

Therefore, the government of Zambia should:

1. Provide resources to orphans and grandmothers to enable them to access essential services

   such as education and health care.

2. Provide antiretroviral drugs to all the people who are HIV positive in order to prolong their

   lives.

3. Assist families affected by HIV/AIDS with financial and psychological support.

4. Increase awareness of the challenges of orphanhood and grandparenting through HIV

education,   religious sermons, and community programs.

5. Promote and mobilise community based resources to fight the HIV epidemic.

6. Include HIV/AIDS beliefs and cultural values in the school curriculum.

7. Include grandparents, especially grandmothers, in HIV/AIDS programs.

6.3 Future Research:

Although the available data allowed the researcher to gain insights into the consequences of a lack of formal and informal support for grandmothers, such as the challenges they face; the data did not enable the researcher to fully address the research questions and objectives. For instance, it is known that education enhances the use of condoms to help prevent people from contracting HIV/AIDS, but the literature seems to contradict this important aspect as it shows that the prevalence rate is higher among the more educated than the less educated, but it does not give a reason for this apparent contradiction. It is not clear why urban areas, where most of the educated live, have higher prevalence rates. Further, the literature is silent on the role of grandfathers as caregivers for HIV/AIDS orphans. It is not known why they are not more actively involved in caregiving. Further research is therefore necessary to address these omissions. Conducting primary research, including interviewing grandmothers is necessary, and

the following questions may enhance our understanding of the full scope of the problem and consequently provide data to address the identified gaps in the body of knowledge:

1. What is the role of grandfathers in grandparenting?

2. How do HIV/AIDS prevalence rates compare between rural and urban Zambia?

3. Why is the HIV/AIDS prevalence rate higher among more educated people?

4. How does the situation in Zambia compare with the experience of grandparents who are caring for AIDS orphans in the rest of Africa?

Conducting research to address these questions will provide information that is necessary in resolving the problems that HIV/AIDS has continued to inflict on Zambia. The government of Zambia will be able to use results from the research to formulate policies and programs to alleviate the adverse effect that HIV/AIDS has brought on the family and grandmothers in particular. Finally, it would be interesting to conduct research on this topic (challenges of grandparenting in HIV/AIDS affected families in Zambia) using other theoretical frameworks, such as the quality of life and compare the results with what this study has brought to the fore.

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