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HIV/AIDS orphans' schooling in post-conflict South Sudan:  
Education-related challenges and coping strategies of orphan children



Master thesis

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## Acronyms and Abbreviation

AIDS	Acquired Immune Deficiency Syndrome
ARC	American Refugee Council
ART	Antiretroviral therapy
ARV	Antiretroviral Treatment
CBO	Community Based Organisation
CSO	Civil Society Organisation
CAPA	Council of Anglican Provinces of Africa
CPA	Comprehensive Peace Agreement
CRC	Convention on the Rights of the Child
EFA	Education for All
ECS	Episcopal Church of the Sudan
FBO	Faith Based Organisation
GoSS	Government of South Sudan
HIV	Human Immune Deficiency Virus
IAVI	International AIDS Vaccine Initiative
IGAD	Intergovernmental Authority on Droughts and Development
IGAs	Income Generating Activities
JRS	Jesuit Refugee Service
KAP	Kajo-keji AIDS programme
KKLC	Kajo-keji Loving Club
KKCH	Kajo-keji Civil Hospital
MDG	Millennium Development Goals
MoF&EP	Ministry of Finance and Economic Planning
MoEST	Ministry of Education Science and Technology
NGO	Non Governmental Organisation
OVCs	Orphans and most Vulnerable Children
PMTCT	Prevention of Mother to Child Transmission
PLHA	People Living with HIV and AIDS
PLHIV	People Living with HIV
PTA	Parents Teachers' Association
SSAC	South Sudan AIDS Commission
SSPO	South Sudan older people's Organisation
UNICEF	United Nations international Children's Fund
UNESCO	United Nations Education Scientific and Cultural Organisation
UNGASS	United Nations General Assembly special Session
UN	United Nations
UDHR	Universal Declaration of Human Rights
WHO	World Health Organisation

**Dedication**

*This thesis is dedicated to All the HIV/AIDS orphans around the world who are struggling to achieve their educational aspirations. May the world hear your cry!*

## **Abstract**

The aim of this study is to provide a picture of the experiences of HIV/AIDS orphans with regard to the challenges they face in attending school, and the ways in which they deal with some of those challenges in the process of schooling in Kajo-keji County, South Sudan. Three objectives were developed for this study. The first is intended to explore the challenges faced by orphans in relation to education. The second explores the initiatives taken by individual orphans to cope with the challenges to their schooling and the third is to understand how various actors within the orphans' communities respond to the orphans' situation. In particular, the third objective looks at the role played by teachers, religious leaders, elders and stakeholders like Governmental and nongovernmental organisations, community based organisation and faith based organisations in helping orphans cope with the challenges they face in the process of schooling.

The methodology adopted for this study is based in a qualitative approach to social research, specifically an ethnographic design in which a variety of methods are used for collecting data, including participant observation, semi-structured interviews and secondary data analysis. Two primary schools were selected as the main sites for data collection, and a total of thirty four participants were interviewed in this study. The resulting data were analysed narratively.

The findings of this study reveal that the HIV/AIDS orphans experience several challenges ranging from food, financial, material, medical and emotional which collectively contribute to affecting their schooling experiences. On a relatively positive note, most of the orphans adopted the leja-leja coping strategy which necessitated that they physically involve themselves in doing income generating activities (IGAs) in order to finance some of their basic and schooling needs. More so, a few of them coped through getting financial and emotional assistance from NGOs, religious institutions, teachers and elders.

The study suggests that, despite or perhaps because of these challenges, orphans can be considered as resourceful individuals. It further indicates that civil society and the Sudanese state can do more to support the HIV/AIDS orphans. One conclusion from the study is that the South Sudan government in collaboration with its partners should intensify their efforts in developing policies and programmes which enhance the educational opportunities of the orphan children, and more so the inclusive culture developed by some primary schools like those in Kajo-keji County which provided 'safe havens' to the orphans.

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## **Chapter one**

### **1.0. Introduction**

The aim of this study is to provide a picture of the experiences of HIV/AIDS orphans with regard to the challenges they face in attending school, and the ways in which they deal with some of the challenges. This chapter presents a global overview of the HIV/AIDS pandemic with a specific focus on the HIV/AIDS orphans' problems in Sub-Saharan Africa, South Sudan and Kajo-keji County, the site where this study was conducted. It has also endeavoured to draw a connection between HIV/AIDS orphans and education in South Sudan. Moreover, stigma and discrimination are some of the issues being given attention to with an interest of showing how these practices have exacerbated and even led to situations of orphan hood in the area of the study. Finally, the rationale of the study with its objectives is presented.

### **1.1 Global overview of the HIV/AIDS pandemic**

HIV/AIDS has become a global challenge in the 21<sup>st</sup> century with its effects being grossly felt at all levels of the society right from the local to the international. Among the worst of its effects is its impact on the family (Ankrah, 1993; Bor, Miller, & Goldman, 2004). This effect alone tends to affect all sectors of the society including the social, economic, political and the cultural settings. As Phiri & Webb (2002) argued, as early as 2002, every 50 seconds a child dies of an AIDS related illness and another becomes infected with HIV. Each day, approximately 3,500 children are infected by, or die from HIV/AIDS (UNAIDS 2000). Moreover, as recent as 2010, both UNAIDS (2010) and IAVI (2010) reports that at least 2.7 million people are newly infected every year. These figures represent a shocking failure on the part of the global community, (Phiri & Webb, 2002). Phiri & Webb further explained that, of the estimated 36.1 million people living with HIV/AIDS world-wide in 2000, 1.4 million are children. Even if a levelling off of new infections occurs, due to the long incubation period of the virus, mortality rates will not plateau until at least 2020, and the proportion of orphans will remain strikingly high at least through to 2030 (Levine and Foster 2000, cited in Phiri & Webb, 2002).

According to UNAIDS/WHO (2010), the number of HIV/AIDS orphans globally is 15 million and 11.6 million of these are in Sub-Saharan Africa alone, completely shedding a

very gloomy picture to the region's future since most of these HIV/AIDS orphans end up not joining school at all or dropping out of school and their next destination is the streets in the cities. Unfortunately, most of them end up in the sex business for survival and eventually dying of AIDS as well. UNAIDS (2002) emphasised that:

Children impacted by HIV/AIDS are also at serious risk of exploitation, including physical and sexual abuse. Isolated from emotional connections with the family, some turn to risky sexual behaviour. Those forced to live on the streets may turn to prostitution and crime as a means to survive. While most of these children were born free of HIV, they are highly vulnerable to infection (UNAIDS, 2002, p.134).

This argument has raised some important points. It highlighted issues of exploitation of HIV/AIDS orphans, particularly the girl child, since some of them are tempted to involve themselves in the sex business for survival. It has also highlighted the fact that most of them become emotionally detached from their loved ones which tend to affect their emotional growth.

Furthermore, the Stephen Lewis foundation (2007) argued that, "in some of the worst-affected countries, AIDS has dramatically lowered life expectancy, crippled health systems, and stunted economic growth" (The Stephen Lewis foundation 2007, p.1). While Subbarao and Coury (2004) argue that, erosion of human capital is probably the biggest risk orphans and vulnerable children face in Africa. They explained that exposure to multiple risks has critical impacts on school enrolments and the health and nutritional status of several million vulnerable children. They emphasised that the probability of not attaining Millennium Development Goal 6: [halting and reversing the spread of HIV] is particularly high for children located in countries experiencing risk-compounding factors-that is, an orphan in a country emerging out of years of civil conflict like the Sudan and subjected to severe shock like losing a parent to AIDS may be very vulnerable to dropping out of school.

In 2007, the number of people living with HIV globally was 33 million according to UNAIDS/WHO (2007) and UNSECO (2010). This number has now risen to 33.3 million (IAVI & UNAIDS 2010), though UNAIDS (2010) argue that the number of new infections worldwide has fallen by 19% in 2009 as compared to 1999. It again argued that the number of deaths among people living with AIDS between 2004 and 2009 globally has declined by

19 %. This is attributed to the increased number of people receiving ARV treatment. As of 2010, five million people have enrolled on the treatment, though 10 million people living with HIV who are eligible for treatment under the new WHO guidelines are still unable to receive it (UNAIDS, 2010). If this situation is not checked through making of more medicines available for those who so much need them, then more people are expected to die of AIDS and eventually more children are left orphans, dramatically reversing the gains made in the recent past.

## **1.2 Sub-Saharan Africa**

Sub-Saharan Africa still bears an inordinate share of the global HIV burden. Although the rate of new HIV infections has decreased, the total number of people living and dying with HIV continues to rise (UNAIDS, 2010, P.25). In 2009, the number reached 22.5 million, 68% of the global total (UNAIDS 2010). Moreover, the highest number of AIDS related deaths in 2009 are still in Sub-Saharan Africa. UNAIDS (2010) argued that, the estimated 1.3 million people who died of HIV related illnesses in sub-Saharan Africa in 2009 comprised 72% of the global total of 1.8 million deaths attributable to the epidemic (UNAIDS 2010, P.25).

If these estimates by UNAIDS are anything to go by, then by implication, more children are left orphans as a results of AIDS in Sub-Saharan Africa than in any other part of the world. UNICEF (2006) argued that an estimated 12 million children aged 0-17 years have lost one or both parents to AIDS, making Sub-Saharan Africa home to 80 per cent of all the children in the developing world who have lost a parent to the disease. These estimates raise the question: Where does Africa's future lie if 15.7 million children are to be orphaned by 2010 as UNICEF has predicted?. Moreover, the same report claimed that:

Even where HIV prevalence stabilizes or begin to decline, the number of orphans will continue to grow or at least remain high for years, reflecting the time lag between HIV infection and death (UNICEF, 2006, p.5).

Furthermore, studies by UNAIDS around the world show that orphans have less of an opportunity of going to school than non orphans. Globally, orphans' school attendance is still staggering at 75% as compared to 79% for non orphans (UNAIDS, 2010:11). More still, the chances that these orphans in school will finish their primary education are still very minimal

due to the difficulty they experience in meeting their material and financial needs associated with schooling, let alone the other thousands who have not been able to enrol to school at all.

### **1.3 HIV/AIDS Status in South Sudan**

The UNGASS and MDG reports (2010) indicate that the current number of people living with HIV in South Sudan is 149,717, and the number of new infections per year is estimated at 16,133 (MDG, 2010, P.1; UNGASS 2010, P.13). The seemingly low HIV prevalence in South Sudan which currently stands at 3.1 % as per the survey conducted in 2007 has made many researchers to classify the region as a generalised low prevalence (UNGASS, 2010). However, the effects of the disease are heavily felt at the community level and particularly by the education sector and more so by the children who have been made orphans by AIDS.

It is important to note that, the low HIV/AIDS prevalence rate in South Sudan is typical of a post- conflict country as Spiegel (2004) argues. According to him, prolonged conflict retards the progression of HIV. He cited examples of countries like Sierra Leone in 2002 with only 0.9 percent prevalence rate and South Sudan with only 2.3 percent prevalence rate in 2003. According to Spiegel, isolation of this population in remote areas, mainly in remote rural areas for a very long time either as IDPs or Refugees due to their limited access and mobility to urban, high prevalence areas is a factor explaining the low prevalence. He, however, warns that this population is more vulnerable to HIV infection in the event of return of peace in the country. This is explained by the fact that the return of peace exposes this population to an interaction with different groups of people coming in from different parts of the world for both official and private business. In the case of South Sudan, the heavy presence of UN peace keepers, traders from high prevalence neighbouring countries like Uganda, Kenya, Tanzania and Ethiopia, sex workers, and expatriate staff could easily accelerate the spread of HIV/AIDS in the country.

This claim has been supported by the data collected for this study. Director-Leo of the South Sudan AIDS commission (SSAC) argued that big towns in South Sudan like Juba, Yei, Maridi, Yambio and border towns like Kajo-keji, Nimule and Kaya are high prevalence areas partly because of the heavy presence of sex workers from the neighbouring countries and partly due to the influx of traders, expatriate staff and the UN peace keepers stationed in these areas. However, it is important to note that, the lack of a nationwide study of the current HIV prevalence in the country has made it very difficult for one to obtain current, reliable and up-

to-date data on the disease in South Sudan. It is, however, possible that the current HIV prevalence rate in South Sudan might have sky-rocketed due to all the above stated factors.

In close relation to the foregoing, Bradshaw, Johnson, Schneider, Bourne, and Dorrington, (2002) argued that, it is useful to consider the HIV/AIDS epidemic as a series of waves which come in mainly four phases where the first and the second phases are almost unnoticeable even when the population is already in the midst of crises. According to them, the first phase is the incidence phase where many people are still newly infected with the HIV and this is closely followed by the second wave which is prevalence. In this phase, many people are already living with the disease and infecting more assuming there is no change in behaviour or no interventions to check the disease.

I therefore think that this is the stage South Sudan is currently in and since limited actions if any are being taken to ascertain the current HIV prevalence rate in the Country to enhance planning and intervention strategies, the population will continue to be kept in this state of ignorance about their HIV status only to be shocked when the disease has already entered its third and fourth phases where very little if any can be done to control it. These third and fourth waves according to Dorrington and colleagues are peaking of AIDS deaths and leaving of children as AIDS orphans.

At County level where this study was conducted, the latest data as per October 2010 obtained by the researcher from Kajo-keji civil Hospital (KKCH) and ARC indicates that, the current number of people living with HIV in Kajo-Keji County, South Sudan is 462 and the number of HIV/AIDS orphans is as high as 291. Much as these figures in numerical terms look very insignificant, the effects of these infections and eventually death of these infected adults on the school children who have no source of income for supporting themselves in school are devastating. This is because, some of these innocent children who have been made orphans because of losing their parents to AIDS are left with no option other than dropping out of school because of difficulty to raise the required money for paying their schools fees and acquiring the necessary school requirements.

The findings of this study however revealed that, much as the government of South Sudan is not practically doing enough in supporting the HIV/AIDS orphans educationally, though the education policy documents guarantees free primary education for all children, at least 80 of the 291 HIV/AIDS orphans in Kajo-Keji County are being sponsored by the IGAD, through



SSAC and KKLC. On a negative note, however, some of these HIV/AIDS orphans are on the verge of dropping out of school because of difficulty to raise the required finances on their own for acquiring the rest of the school materials ranging from scholastic equipment to school uniform since the scholarship only caters for school fees. The relatively positive part of the study findings was that most of the HIV/AIDS orphans have adopted what I referred to as the “leja-leja coping strategy” for coping with their challenges where they involve themselves in doing small scale income generating activities (IGAs). More so, a few of the orphans living in the orphanage centre are being supported in their education through providing for them food, accommodation, paying their school fees and meeting all their material and to some extent psychological needs.

#### **1.4 HIV/AIDS’ orphans and education in South Sudan**

The UNGASS report (2010) indicates that the current number of HIV/AIDS orphans in South Sudan is 31,351. Of this number, the report argued that only 490 of them were supported in school by an organisation called South Sudan Older people’s organisation (SSPO) with support from international partners like HelpAge international until 2008. In 2009, when OldAge international wrapped up work in the South Sudan, SSPO could not enrol new OVCs except some 20, the report argued. With only 510 OVCs supported educationally which represents 1.6 percent of the total number of HIV/AIDS orphans in South Sudan, this support was like a drop in a drum (UNGASS, 2010).

A close analysis of the above data means that with a proportion of nearly two AIDS related orphans of 100 receiving educational support, about 98 percent of the HIV/AIDS orphans were either out of school or supported through the extended family system (UNGASS, 2010). Furthermore, it is worth noting that though IGAD through SSAC has started supporting an additional 80 HIV/AIDS orphans in Kajo-keji County in 2010 in a pilot project, the overall picture of the HIV/AIDS orphans achieving their educational aspirations still look dark. This is explained by the fact that it is not clear as for how long this support will continue and whether more will be considered for the scholarship next year.

#### **1.5 Single and double orphans**

The AIDS epidemic in sub-Saharan Africa is affecting children in many harmful ways, making them vulnerable, leaving them orphaned and threatening their survival. In the most affected countries in this region, children are missing out on what they need for survival, growth and development. Many scholars have not agreed on a single definition of the term

orphan. This disagreement mainly stems from the age limit under which an individual is regarded as a child. Many scholars limit the definition of an orphan to a child who is under 15 years and has lost one or both parents to AIDS (Dorrington et al 2002; Foster 1995 & Preble, 1990; in Ntozi, 1997);) while others argue that a person remains a child until the age of 17 (Ntozi 1997; Paige, Mark and Johnson (n.d) & UNAIDS/WHO, 2010), and yet for others, only a child who has lost his/her father can be regarded as an orphan (Ntozi and Mukiza-Gapere, 1995). They argued that in all the six districts in Uganda where they conducted their study in, a child with a father was not considered an orphan because the father would marry other wives who would look after his children using his wealth. Citing examples of the Bakiga of Kabale and Banyankore of Mbarara both in Uganda, they claimed that the father of the deceased wife would offer the widower another daughter to replace her sister and look after the orphans.

Furthermore, orphans are classified into maternal, paternal, single and double orphans. A maternal orphan is a child who has lost his/her mother and a paternal orphan is a child who has lost his/her father. A single orphan can be a maternal or a paternal orphan who has lost either of the parents to AIDS while a double orphan is a child who has lost both parents to AIDS (UNESCO 2002). However, for this study, I define an orphan as a child under the age of 18 who has lost either both or one of the parents to AIDS. This is because the interim constitution of South Sudan (2005) states that the maturity age for a child is 18, meaning that any person under the age of 18 is constitutionally regarded as a child.

It is worth arguing that, the AIDS epidemic puts children at risk physically, emotionally and economically. All children are indirectly affected when their communities, and the services these communities provide, are strained by the consequences of the epidemic. Nurses, doctors, teachers and others can become ill and die from AIDS, affecting health care, education and other basic Services. Children are directly affected in a number of ways. They may live at high risk of HIV; they may live with a chronically ill parent or parents and be required to work or put their education on hold as they take on household and care giving responsibilities; their households may experience greater poverty because of the disease; and they can be subject to stigma and discrimination because of their association with a person living with HIV (UNICEF, 2006). In addition, as parents and other family members become ill, children take on greater responsibility for income generation, food production, and care of

family members. They face decreased access to adequate nutrition, basic health care, housing, and clothing (UNESCO, 2002). All these affect their school attendance and performance negatively. In the worst case scenario, some end up dropping out of school or not joining school at all.

### **1.6 Stigma and discrimination**

As will be seen in the findings chapter, Project officer-Deborah argues that many people living with HIV in South Sudan face experiences of stigma and discrimination on daily basis. According to her, though some HIV/AIDS positive people like her have lived with the virus for over 20 years and still show no sign of infection, some of the members of SSNeP+ have lost their lives within a very short time due to experiences of extreme stigma and discrimination at their homes and the community at large. This argument explains in clear terms how AIDS stigma is still a problem around the world.

Indeed, AIDS stigma exists around the world in a variety of ways, including rejection, discrimination and avoidance of HIV infected people; compulsory HIV testing without prior consent or protection of confidentiality and violence against HIV infected individuals or people who are perceived to be infected with HIV. Stigma-related violence or the fear of violence prevents many people from seeking HIV testing, returning for their results, or securing treatment, possibly turning what could be a manageable chronic illness into a death sentence and perpetuating the spread of HIV hence leading to an increase in the number of HIV/AIDS orphans (The Medical News, 2010).

The persistence of discriminatory practices against HIV positive persons among some south Sudanese is not an isolated incident in Sub-Saharan Africa. Skinner and Mfecane, (2004) argued that as with most other countries worldwide, South Africa has reported a large number of incidents of stigma. These include the murder of Gugu Dlamini an AIDS activist in December 1998 for openly stating that she was HIV positive, the murder of Mpho Mtloung together with her mother by her husband for revealing her HIV status; not allowing HIV-positive children into schools; and rejection of HIV positive persons from families (Skinner & Mfecane, 2004).

In reference to the foregoing, though the exact style of killing varies, these practices reported by Skinner and Mfecane against the HIV positive persons in South Africa are not very

different from what has happened to the same group in South Sudan. Three of my participants working with organisations responsible for the welfare of people living with AIDS reported having lost two members of one of the associations they support (KKLC) due to stigma and discrimination against them by their families. For example, apparently one was not allowed to continue with her ART treatment and the other was allegedly denied food, accommodation and company by the family members. These acts led to rapid deterioration of their health resulting to death.

The important lesson one can learn from the above arguments is that AIDS stigma is real and it does exist. However, with concerted efforts put by governments, NGOs and the community at large to fighting stigma and discrimination, the world can witness a reduced incident of HIV positive persons dying of AIDS. As Project officer -Deborah has argued, “We will not continue having HIV/AIDS orphans because all their parents will remain alive to care for them”. This comment by Deborah certainly seems simplistic as AIDS deaths may continue to occur due to frequent attacks by opportunistic infections on the HIV infected persons as their immunity get weakened. However, it highlights the importance of living in an environment with reduced stigma by the sero-positive members of the society.

Many research studies have found a significant number of respondents who want people living with HIV (PLWH) to be clearly identifiable, to be separated from the rest of the population, or excluded from contact in schools, work and social institutions (Strebel & Perkel, 1991). These findings are consistent with the findings of this study. For example, Coordinator-Ayet explained that, in one of the talk shows they conducted, some of the community members argued that she and her group of people living with AIDS should be relocated away from the communities they currently live in and get settled in an area between Kajo-Keji and Juba counties where no other people live.

Moreover, in one of my interviews with an ARC staff member, I was informed that the community members in the community they work in demanded that all the HIV positive persons should be relocated away from the community.

Both arguments from Coordinator-Ayet and the ARC staff member point to the same thing, and that is the desire on the part of some community members to relocate all the HIV positive persons away from the general population. This is a bad signal against the sero-positive

members of the society, though it also points to that assertion that these members are simply ignorant of what HIV/AIDS is and therefore, their perceptions can be easily changed by provision of proper education to them about HIV/AIDS.

Reports of stigma are pervasive, extending even to the health professions. Some health professionals have refused to treat people with AIDS, on the grounds of possible risk of infection (Christian aid, 2008). This is typical of some of the health professionals in South Sudan who argue that “why do we waste our time on people who are already rotten”? (Coordinator-Ayet) and “who will compensate us if we get infected in the process of treating an HIV positive person” (Christian aid, 2008, pp. 12-14).

Children orphaned or rendered vulnerable by AIDS are likely to experience increasing stigmatisation. They faced verbal and physical discrimination at schools and in the community (Streak, 2001b). Orphans have also been identified as a major security threat for the future (Schönteich, 2002). Stigma would clearly worsen the situation of orphaned and vulnerable children, excluding them even further from resources and support. (Skinner and Mfecane, 2004:160). Moreover, the more they are excluded from resources and support, the more vulnerable they become. This situation forces some of the orphans to adopt negative coping strategies like stealing and involving themselves in the sex business. This may lead some of them to get infected and eventually dying of AIDS. On a positive note however, such negative coping strategies have not yet been adopted by the orphans in this study as I will show in the discussion chapter.

### **1.7 Aid, its conditionality and effect on local community’s behaviour**

Aid as the name suggest refers to any support given to someone in need. It can be financial, material, emotional and inform of food. In the context of this discussion therefore, the focus is on financial aid. It is worth noting that the term financial Aid is a catch-all term referring to “any programme that offer money to assist with the costs associated with being a pupil or a student” (Hewitt, n.d). This includes tuition help, scholarship, living stipends and textbook costs. Aid can come from any of these sources. For instance state, local and federal governments, private charities and many more. In reference to this study, the kind of aid referred to is financial aid from private charities and governmental including Nongovernmental organisations involved in supporting HIV/AIDS orphans in South Sudan.

Aid is usually associated with a double effect on its recipients. One of this effect stem from the conditions with which Aid usually come and second is from the culture of dependence it cultivates in its recipients; hence making the recipients more vulnerable. Though education aid is well known for its benefits of keeping needy children in school and eventually helping them to achieve their educational aspirations, it has for long also been associated with causing school drop-outs among its beneficiaries. As if to agree with this argument, one of the participants in this study argued that:

One of the challenges in depending on charitable support is for those orphans who do not perform well in school. Since the money comes from well wishers, they always demand that their money should be used for paying those orphans who are excelling academically. Therefore in this situation, when an orphan repeats the same class twice and could not pass, then such an orphans' scholarship is stopped which make many of them to drop out of school (Yaba, a participant)

From the above, one can deduce that, Aid; particularly coming with unrealistic conditions on its recipients and in the case for the OVCs is counter-productive because it does not deliver the expected benefits to its intended beneficiaries.

In addition, Aid is also known for its effects of creating the culture of dependence syndrome among parents and community members, hence making them and their children more vulnerable in an event when the Aid ceases to come. This is because, these individual parents/guardians may have not developed skills for generating income in order to support their children in school, hence leading to school dropout among the OVCs. Some of the participants in this study argued that:

Much as the social welfare department supports the HIV/AIDS orphans, this support is not made public because a human being is a human being. If free education is declared for orphans, even those parents who are alive will claim that they are taking care of orphan children at their homes. You will realise that “even me, I will say that I have orphan children who need that support (Director-Madut, a participant).

Director-Ole seem to strongly agree with Director-Madut and argued that, “free things can be a disease .We are making it confidential so that it cannot create a crisis of free education for all. Free things are a disease and we do not want this support to create a dependence syndrome” (Director-Ole, a participant).

The above arguments seem to suggest that Aid can have negative consequences in the work culture of community members. This therefore seems to suggest that, for a sense of continuity to be created in extending support to the orphans, guardians need not to give up their

livelihoods in the event of some external support extended to the children under their care so that when the external support ends, they are able to continue supporting the orphans on their own.

Therefore, in order to check against the negative consequences of Aid, stakeholders in positions of responsibility and particularly those acting as gatekeepers to the aid need to check and analyse the kind of conditions a given aid is associated with. This close scrutiny of the terms and conditions with which aid comes can enable the stakeholders to either accept or reject the aid and wherever it is possible, re-negotiate the terms so that they are less harmful to the beneficiaries. As Yaba had pointed out, the orphans in the orphanage centre in Kajo-Keji are the most affected as their livelihoods depended on aid from some foreign donors. This seems to explain the apparent change of attitude by Yaba from relying entirely on aid to development of self reliant skills in the orphans. He now strongly advocates for involvement of the orphans in the orphanage centre in food production both for themselves and wherever it is possible, sell the surplus for meeting some of their educational needs.

### **1.8 Inclusion and Inclusive Education**

Recognition as a member of a group which creates feelings of inclusion and belonging in the individual is certainly what everybody needs. Exclusion creates fragmentation and disunity in a society while inclusion creates unity and gives the society strength to fight an apparent common threat (Osler and Starkey, 2005) .Such is the nature of society required in Kajo-keji County, South Sudan in this era of AIDS which is tearing the community apart due to the fault lines created among the members as a result of stigma and discrimination.

I argue that, creating an inclusive society by developing an inclusive behaviour in the members of the society is one of the important strategies the South Sudan society and Kajo-keji county in particular needs in order to:-reduce HIV infection rates and create an inclusive and a conducive environment for the HIV/AIDS orphans academic progress. The above arguments are based on the fact that any society which intentionally or unintentionally excludes some of its members is a breeding ground for stigma and discrimination. In a society where people are living with HIV/AIDS, as the level of stigma and discrimination rises, a behaviour of denial develops among those members who are HIV positive (Christian aid, 2008). This has the effect of creating a false impression in the community that HIV/AIDS is non prevalent. In other words, the epidemic becomes invisible (Asiedu, 2007; Christian aid, 2008 and Perry, 2006). Unfortunately, as Christian aid (2008) and Perry (2006)

argue, this is the time when HIV infection rates go high as preventive measures against the spread of the disease like condom use, abstinence and faithfulness are neglected. This eventually leads to occurrence of more AIDS related deaths and leaving of many children as orphans in the society.

On the other hand, the creation of an environment which is tolerant leads to the creation of spaces like schools where young people learn to be open minded. Orphans thrive in such environments, go to school, and thereby expose their fellow students and the schools and other organisations or institutions to living with people living with HIV/AIDS, thereby contributing to creating an inclusive environment.

UNESCO, (2008) defines inclusion as “a process of addressing and responding to the diversity of needs of all learners through increasing participation in learning, cultures and communities and reducing exclusion within and from education...”. Two things are worth emphasising in this definition. Addressing and responding to the diversity of learners needs and reducing exclusion within and from education. The implication of this to educational institutions is that school administrators need to develop inclusive policies with an aim of reducing practices of stigma and discrimination as hinted by some of my participants.

Moreover, Nsubuga and Jacob (2006) argue that this inclusive approach helped in creating a conducive learning environment for the HIV/AIDS orphans in Uganda. On the other hand, UNSECO (2009) argues that inclusive education is a process of strengthening the capacity of the education system to reach out to all learners. As UNESCO has put it, once the capacity of the education system is strengthened to reach out to all learners, and then HIV/AIDS orphans like the ones in India as mentioned in Petney’s (2010) study will have a conducive environment to remain in school and learn.

### **1.9 The Rationale of the study**

Education is a right to every child (UDHR, 1948). Article 26 of the universal declaration of Human Rights states that, “everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages” (UDHR, 1948 in Osler and Starkey, 2005, .p.187). Similarly, article 28 of the UN convention on the rights of the child specifies that, states which are party to this convention should make primary education compulsory, available and free to all. However, in some parts of the world and for various reasons, this right is not guaranteed to every child in practice.



HIV/AIDS orphans are some of the children who have been and are still missing out the opportunity to formal education (Kelly, 2000; Petney, 2010 & UNGASS, 2010). This is explained by the fact that these children are faced by many challenges ranging from stigma and discrimination on one hand, to food, financial, material, medical and emotional challenges on the other. The latter is explained by the fact that, some of them have lost both their parents to AIDS, while some have lost one and are fully engaged in caring for the surviving one using all the family resources. By the time both parents are dead, all the family resources which could have supported them have been used up. This situation has made it very difficult for many HIV/AIDS orphans to enrol to school and some of them who have enrolled end up dropping out of school simply because they cannot afford the financial and material cost of education.

It is from this background that this study has been designed to explore the education-related challenges and coping strategies of HIV/AIDS orphaned children so that we may learn from the positive coping experiences of these orphans.

## **1.10 The Research focus**

### **1.10.1 Aim**

The aim of this study is to provide a picture of the experiences of HIV/AIDS orphans with regard to the challenges they face in attending school, and the ways in which they deal with some of the challenges. The specific objectives below have been formulated to help in the achievement of this aim and this is followed by the research questions.

### **1.10.2 Objectives of the study**

The objectives of this study are:

1. To explore the challenges faced by orphans in relation to education
2. To explore initiatives taken by individual orphans to cope with the challenges in the process of schooling
3. To understand how various actors within the orphans' communities respond to the orphans' situations. In particular the role teachers, religious leaders, elders and stakeholders like Governmental and nongovernmental organisations, community based organisations, and faith based organisations play in helping orphans cope with the challenges they face in the process of schooling

### 1.10.3. **Research Questions**

The following research questions guided this study:

- What challenges do HIV/AIDS orphans face in relation to furthering their education?
- What initiatives have the orphans taken to cope with the challenges and continue with schooling?
- What roles have teachers, religious leaders, elders and stakeholders like Governmental and nongovernmental organisations, community based organisations, and faith based organisations played to help HIV/AIDS orphans cope with their challenges and continue with schooling?

### 1.11. **Significance of the study**

It is my conviction that this piece of work will be an asset to everyone who will have some access to it. These among others will include researchers, teachers, students, development workers and all the HIV/AIDS orphans around the world. The experiences gained and lessons learned from these orphans and the various stakeholders involved in the study could be useful for helping other orphans in the future who may find themselves faced with similar challenges. In addition, since this is an area which has not yet been extensively explored by researchers, in South Sudan, this piece of work could be a foundation for other researchers who may want to explore the same field further. Likewise, it may be useful for Aid agencies, community based organisations and faith based organisations that may benefit from the perspectives offered here in expanding upon their understanding and support of orphans.

### 1.12. **Organisation of the thesis**

This thesis is organised in to five chapters. Chapter one mainly has set the stage and presented a global overview of the HIV/AIDS pandemic with a specific focus on the HIV/AIDS orphans' problems in Sub-Saharan Africa, South Sudan and Kajo-keji County, the site where this study was conducted. It has also endeavoured to draw a connection between HIV/AIDS orphans and education in South Sudan. Moreover, stigma and discrimination are some of the issues being given attention to with an interest of showing how these practices have led to leaving many children as orphaned. These issues form the background from which the rationale of the study with its objectives were presented

Chapter two presents a discussion of the methodology used in this study. A qualitative research approach with bricolage design was applied in this study. The chapter further presents how access to the field was negotiated. It also presents a vivid discussion of the various methods used for collecting the data and winds up the discussion by presenting the challenges faced in the field.

Likewise, chapter three outlines the field findings which are presented in two parts. Part one presents financial, material, food and health related challenges faced by the HIV/AIDS orphans and how they cope with these challenges mainly using the leja-leja coping strategy. Part two presents stigma and discrimination and their related challenges which are experienced by both the orphans and their sick surviving parents and explains how these experiences affect their academic performance at school.

Chapter four engages in a discussion and analysis of the field findings. Like the findings chapter, this chapter is also divided into two parts. Part one discusses stigmatisation and discrimination within various arenas in the community. Significant in this part is the somewhat claim by the HIV positive members of the society that, the root cause of death among HIV/AIDS patients is stigma and discrimination, rather than the opportunistic infections which attack them at the advanced stages of the disease. Moreover, this claim is being supported by studies conducted by (Asiedu 2007; Link and Phelan 2006 & Skinner and Mfecane 2004). However, central to this study is the fact that the death of these adults results in leaving many children as orphans. Part two discusses the coping strategies adopted by the HIV/AIDS orphans and the difficult conditions of especially the female orphans. However, of interest is the fact that most of the orphans adopted what is referred to here as “the leja-leja coping strategy” which enabled them to remain in school.

The final chapter concludes by presenting some concluding remarks on the role of different actors in reducing the plight of the HIV/AIDS orphans. This brief outline of the thesis lead us to chapter two, which mainly discusses the methodology used for conducting this study.

## **Chapter two: Methodology**

### **2.0. Introduction**

This chapter presents the methodology used for conducting this study which was aimed to provide a picture of the experiences of HIV/AIDS orphans with regard to the challenges they face in attending school, and the ways in which they deal with some of the challenges. According Cohen et al, (2000) the aim of methodology is to help us understand in the broadest possible terms, not the products of scientific inquiry, but the process itself (Cohen et al, 2000, p.45). In other words, methodology is a foundation for building and identifying the types of procedures needed for conducting a given study. As Kvale (1996) argues, methodology is more than the methods used for gathering data. It includes the whole systematic process from thematizing to reporting. Since the purpose of this study is to explore the education related challenges faced by HIV/AIDS orphans and how they cope with these challenges in the process of schooling in post-conflict South Sudan, then qualitative research methodology is seen to be the best method to use so that the researcher is enabled to understand the world the HIV/AIDS orphans are in.

The aim of this chapter is to discuss the methodology that was used for conducting the study. In summary, the chapter discussed ethnography as a research design used for collecting data about the education-related challenges and the coping strategies of the orphan children. This is followed by conventional elements of ethnography such as access to the field and the selection of participants, among others, with the third section focusing on narrative elements of ethnography. The last part of the chapter deals with reflexivity and issues of credibility, trustworthiness and authenticity, and also briefly highlights the limitations of the study. First, however, the next section discusses qualitative research methodology

### **2.1. Qualitative Research methodology**

The methodology adopted for this study is informed by a qualitative research approach. Qualitative research is more usually regarded as denoting an approach in which theory and categorization emerge out of the collection and analysis of data (Bryman, 2008, p.370). Most obviously, qualitative research tends to be concerned with words rather than numbers, but three further features were particularly noteworthy. Firstly, an epistemological position described as interpretivist, meaning that in contrast to the adoption of a natural scientific model in quantitative research, the stress is on the understanding of the social world through an examination of the interpretation of that world by its participants; second, an ontological

position described as constructionist, which implies that social properties are outcomes of the interactions between individuals, rather than phenomena ‘out there’ and separate from those involved in its construction, and thirdly, an inductive view of the relation between theory and research, whereby the former is generated out of the latter (Bryman, 2008,p.366).

To take the discussion further, I would like to throw more light on the epistemological and ontological assumptions of this research strategy. An epistemological issue concerns the questions of what is or should be regarded as acceptable knowledge in a discipline (Kvale, 2009, p.47). As Bryman (2008) argues, a particularly central issue in this context is the question of whether the social world can and should be studied according to the same principles, procedures and ethos as the natural sciences. The position that affirms the importance of imitating the natural sciences is invariably associated with an epistemological position known as positivism which advocates the application of the methods of the natural sciences to the study of social reality and beyond; though it ought to be noted that “it is a mistake to treat positivism as synonymous with science and the scientific” (Bryman, 2008, p.14). This is because positivism entails elements of both a deductive approach such as its position that the purpose of theory is to generate hypothesis that can be tested and that will thereby allow explanations of laws. Similarly, it has an inductive strategy in its position that knowledge is arrived at through the gathering of facts that provide the basis for laws (Bryman, 2008).

However, considering the qualitative nature of this study, it is the second epistemological position of interpretivism which is going to be adopted. As Bryman (2008) argues, interpretivism is a term given to a contrasting epistemology to positivism and it is predicated upon the view that a strategy is required that respects the differences between people and the objects of the natural sciences (Bryman, 2008, p.15). The term subsumes the views of writers like Von Wright (1971) and Max Weber (1864-1920) who share the view that the subject matter of the social sciences for example people and their institutions is fundamentally different from that of the natural sciences. They then argued that the study of the social world requires a different logic of research procedure that reflects the distinctiveness of humans as against the natural order (Bryman, 2008). Interpretivism has several philosophical roots, among which is phenomenology.

Phenomenology according to Bryman, (2008) is a philosophical perspective that is concerned with the question of how individuals make sense of the world around them and how in

particular the philosopher should bracket out preconceptions concerning his /her grasp of that world (Bryman, 2008, p.697). This definition seems to suggest that, individuals constantly reflect and make sense of the environment around them. In reference to this study, it seems to suggest that, the individuals [HIV/AIDS orphans] make sense of the demands [challenges] in their environment and adopt coping strategies to these demands so as to enable them lead a fairly normal life. Thus phenomenology provided the philosophical assumptions that enabled me to draw from the orphans' life worlds to construct an understanding of their challenges and coping strategies.

Drawing on some elements of phenomenology in for the methods of this study is predicated on the view that social reality has a meaning for human beings and therefore human action is meaningful for them and they act on the basis of the meaning they attribute to their acts and to the acts of others (Bryman, 2008). In reference to this study, the use of phenomenological elements enabled the researcher to use interviews and observations to explore why some orphans adopted certain kinds of coping strategies. As Bryman, (2008) suggests, it is the job of the social scientist to gain access to people's common-sense thinking and hence to interpret their actions and their social world from their point of view. Phenomenology facilitated this access and interpretation of the orphans' and my experiences of their challenges, and through reflection, made it available for qualitative analysis.

Furthermore, when discussing the ontological assumptions of qualitative research as a research strategy, the question of whether social entities can and should be considered objective entities that have a reality external to social actors, or whether they can be and should be considered social constructions built up from the perceptions and actions of social actors, is important to ask. In addressing this question, it is worth comparing the two ontological positions of objectivism and constructionism. Objectivism is an ontological position that asserts that social phenomena and their meanings have an existence that is independent of social actors. In other words, objectivism implies that social phenomena confront us as external facts that are beyond our reach or influence; while constructionism is an ontological position that asserts that, social phenomena and their meanings are continually being accomplished by social actors. This implies that, social phenomena and categories are not only produced through social interaction, but that they are in a constant state of revision (Bryman, 2008), meaning that the researcher and his or her participants are in a constant state

of constructing and reconstructing knowledge. This way of looking at the researchers' role also implies that the researcher always presents a specific version of social reality, rather than one that can be regarded as definitive (Bryman, 2008). It is on these grounds that this study has adopted a narrative form of writing so that the data can be presented from different perspectives, in other words, from my perspective as a researcher and from the perspective of the participants. As will be highlighted later in this chapter, these different representations, I argue enables the text to validate itself through the depth of the information it provides.

Therefore, in reference to the foregoing discussion, it is worth emphasising here that, a qualitative research approach is chosen for this study in line with the nature of the research topic that requires participants to express themselves and tell their views and experiences about the education- related challenges they face. Furthermore, the use of a qualitative research approach has enabled me to get a deeper understanding of the initiatives the HIV/AIDS orphans have taken to cope with their challenges. It has also enabled me to get the perspectives of the educators and the other stakeholders on the various approaches they have employed in helping these HIV/AIDS orphans cope with their challenges and continue with schooling. In other words, the approach helps the researcher to understand the world in which participants live. It is thus essential to enter into a conversation with the participants in a natural setting (Kvale, 2009).

In summary, this section highlighted the significance of adopting qualitative research strategy for this study. An emphasis was placed on discussing the importance of adopting constructionism as an ontological position in qualitative research in this study which asserts that, social phenomena and their meanings are continually being constructed by social actors and are in constant state of change. The next section discusses the research design.

## **2.2. Research Design**

Since very few studies if any of this nature have been conducted before in South Sudan, an ethnographic research design was adopted for this study. Ethnography is a research method in which the researcher immerses him/herself in a social setting for an extended period of time in observing behaviour, listening to what is said in conversations both between others and with the field worker and asking questions (Bryman, 2008, p.693). In this study, ethnographic elements are used because they help the researcher to investigate through observing events in the field again and again and engaging the participants in a discussion on the same observed

scenarios with an aim of getting a clearer understanding of the situation under study (Bryman, 2008). In reference to this study, ethnographic elements were used in order to explore the education-related challenges faced by the HIV/AIDS orphans and the strategies they have developed for coping with the challenges both on their own and with the help of other stakeholders.

In short, I speak of elements of ethnography instead of complete ethnography because complete ethnography involves a prolonged period of study in the field by the researcher, which has not been the case in this study. My field work lasted for about two months and half, which is rather less than the period to be taken by a complete ethnographic study. Nevertheless, I was able to use ethnographic elements such as direct, first hand observation of daily lives of my participants and interviewing them.

## **2.3. Conventional elements of Ethnography**

### **2.3.1 A. Access to the field**

Though Hamersley and Atkinson 2007, p.104 argued that gaining access to the field and to informants can be quite complex and sometimes as difficult as negotiating access to setting, this has not been the case for the most part of my field work. My access to the field has been relatively easy for two reasons. One is that I was conducting the research in my home county so I already knew many schools before the start of this study though I did not know that these are schools with HIV/AIDS orphans. Secondly, cooperation from the local authorities who were the gatekeepers made it easier to gain information about the HIV/AIDS orphans and the organisations/ associations supporting these HIV/AIDS orphans in the County. However, despite my familiarity with most people in the field, I still needed the introduction letter from Oslo University College to assure most of the gatekeepers that I was a student from the college and therefore collecting the data for academic purposes, considering the sensitivity of my topic and the type of participants I wanted to collect my data from.

HIV/AIDS has still remained a very delicate topic to discuss considering the stigma and discrimination directed at those who are HIV positive or those who are related to people who are HIV positive. In some societies, even those who are not infected are associated with their parents or relatives who are infected. Therefore, because of this, gatekeepers were not ready to allow one to go and interact with this category of participants without having a clear



knowledge of the purpose of such an interaction since the information collected may be used for harming these infected or affected individuals.

However, despite all these possible barriers, my access to the field became easy particularly after my first meeting with the County Education Director, and after having clearly stated the purpose of my study to him. Indeed, as (Gall et al. 2007 in Kenyi, 2009) has suggested, a researcher has to follow appropriate channels of authority to gain access to the informants. Similarly, my meeting with the head of the social welfare department proved very valuable on the grounds that, he was very cooperative and opted to travel with me to all the locations where we could either find the HIV/AIDS orphans or get exact information on where to locate the HIV/AIDS orphans.

The most important gatekeepers were the ones I met at an organisation which I will refer to as Kajo-keji loving club (KKLC). This is actually the main office of an association of people living with HIV/AIDS in the County and it is from this office that I obtained all the information regarding the schools where the HIV/AIDS orphans can be found. They also provided me with the number of HIV/AIDS orphans at each school. This made it easier for me to then decide on which schools I should go to based on the information I already had at hand. Hope and Liberty [pseudo names] primary schools were then chosen as my sites for the study since they have a fairly big number of HIV/AIDS orphans and secondly, they were not too far away for me to reach every morning at 8:00 am on my motor bike.

Though both schools accepted that I can carry on with my study in my first meeting with the management, things turned out quite differently in my second visit to one of the schools and this is basically because of bureaucratic procedures. On my arrival at the school the following Monday with a hope of beginning my participant observation, I was told that, “Haaa; my friend, you cannot begin that activity yet. I later on talked with my Bosses and they told me that since you are taking more than one month in the school, the introductory letter you brought to us from your university is not enough. You need to do one important thing for you to be given the permission to enter the classes”. I was puzzled, because I didn’t expect to hear this reflecting back to our discussion in my first meeting with them. However, the condition I was required to fulfil first was quite easy and I did it in a matter of minutes, since the school had both a computer in the Head teachers office and a printer. All they required from me was to formally write an application letter to the Head teacher of the school stating clearly the objectives of the study and all the activities I was going to carry out in the school with the

HIV/AIDS orphans and the teachers during the period I would be with them. I promptly did this and the matter was settled. The only impact of this action was that it had delayed the start of my participant observation exercise by one day; however, this kind of action didn't surprise me, considering the high level of formality in every official business in the Sudan, which I was very familiar with. With the selection of the research site completed, I could now go about selecting the other participants to the study.

### ***2.3.2 Selection of participants***

I had to use purposive rather than random sampling for the selection of my participants for this study. This implied that participants selected to take part in the study had been deliberately identified as relevant in relation to the subject of inquiry as opposed to chosen randomly. According to Patton (2002, p.230), the term purposive sampling “focuses on selecting information- rich cases whose study will illuminate the questions under study”. In the same way, Bryman (2008) argues that the goal of purposive sampling is to sample cases/participants in a strategic way, so that those sampled are relevant to the research questions that are being posed (Bryman 2008,p.415), though this approach does not allow the researcher to generalise the findings to the whole population. However basically, I had undertaken purposive sampling in order to gain as much knowledge as possible about the context and the persons under study. In short, for this particular study, the participants I had chosen were the HIV/AIDS orphans themselves, and also members of the community who have knowledge about the challenges HIV/AIDS orphans face and how they try to cope with these challenges. The latter group included elders, religious leaders, and individuals working with NGOs, CBOs, CSOs, to mention but a few. The next section discusses the criteria used for selecting the participants.

### ***2.3.3 Selection criteria***

I used the following criteria for the selection of my participants for the study. To begin with; the HIV/AIDS orphans were my main focus in the study and particularly those in primary school. Similarly, my focus was on HIV/AIDS orphans between the ages of 11 to 16 from primary three to primary seven [that is, grades three to seven]. Teachers selected were to be those teaching from primary three to seven in the classes where these HIV/AIDS orphans are present. These teachers should have knowledge of the HIV/AIDS orphans in their classes. Senior women teachers and Head teachers were selected according to the schools and this is because of their central role in the lives of these HIV/AIDS orphans. For the senior women

teachers, they describe their roles as that of guidance and counselling in the schools, and act as nurses and mothers to these HIV/AIDS orphans. Project officers and project coordinators selected for this study are those working with Non Governmental and Community based organisations working in the area of HIV/AIDS and their roles include the aspect of care and support for the HIV/AIDS orphans. Some directors are selected because of their central roles in the running of the schools in the entire county and others are selected because of their direct involvement in supporting the HIV/AIDS orphans in the County and state AIDS commissions' offices. The caretakers/guardians/elders selected are those directly involved in care, support and up-bringing of these HIV/AIDS orphans and finally the religious leaders are selected partly because of the spiritual support and the guidance and counselling services they give to these HIV/AIDS orphans who live within their areas of work and partly because of the occasional financial and material support they give to the HIV/AIDS orphans. The following section presents the category of participants selected for the study.

#### **2.3.4 Category of participants in the Study**

I had selected a total of 34 research participants for this study. As Patton (2002, p.321), has argued, informants are people who are particularly knowledgeable about the inquiry setting and people whose insights can prove particularly useful in helping an observer understand what is happening and why. As mentioned, my participants included HIV/AIDS orphans, Head teachers, Deputy Head teachers, teachers, senior women teachers, Heads of departments, project coordinators, project officers, religious leaders, caretakers/guardians/elders and Directors at both County and state levels of the government in South Sudan. This group of participants was selected because they were knowledgeable about the experiences of the orphans that I was investigating for answering my research questions. The table below summarises the sample selection divided into categories according to sex.

**Table 1: Number of participants selected for interview in each category**

<b>Informants</b>	<b>Male</b>	<b>Female</b>	<b>Grand total</b>
HIV/AIDS orphans	3	4	7
Teachers	3	2	5
Senior Woman Teachers	0	2	2
Head Teachers	2	0	2

Deputy Head Teachers	1	0	1
Project officers	3	2	5
Project Coordinators	1	2	3
Directors (County and state)	3	0	3
Head of Departments	1	0	1
Caretakers/Guardians/Elders	1	2	3
Religious Leaders	1	1	2
<b>Total</b>	<b>19</b>	<b>15</b>	<b>34</b>

**Source: Field visit report**

### 2.3.2. B. Data collection Methods

This study used semi-structured interviews as its primary method of data collection. This method was supplemented by aspects of participant observation and document analysis. The use of these methods, more particularly the semi-structured interviews generated rich and in-depth descriptions of the phenomena being studied. The sections below present a detailed description of these methods.

#### 2.3.2.1. *Participant observation*

This method of data collection has the potential to yield relevant valid data as the researcher is fully involved with the participants and observing all the activities they are engaged in both in their happy and sad moments. As Bryman (2008) explains, this method of data collection is advantageous in that, the researcher is fully immersed in the social setting. This enables the researcher to make regular observations of the behaviour of the members in their natural environment and more so, listens to and engages in conversations with them. In order to get a picture of the education related challenges facing the HIV/AIDS orphans, I had to immerse myself fully in to the setting. As Denzin and Lincoln (2000) argued, by immersing oneself in the setting, the researcher begins to understand the context better and chances are that he/she will discover things that otherwise would have been missed if interviews alone were used to collect data.

In this regard therefore, I decided to carry out both structured observations in the classroom and non-structured observations outside the classrooms, mainly during the short breaks and lunch times. In the classroom, I usually went in together with the subject teacher at the start

of the lesson. Initially, the teacher had to introduce me since I was a stranger to those pupils who were not participants in my study. It usually followed that the teacher would greet the class and ask me to do the same and also to tell them my name. However, this information was not enough for most pupils. They would ask the teacher, “who is he exactly and his position”? The teacher would reply that he is a fellow pupil like you who has come to also learn; only that he is a “Big pupil”. Then I would also take my seat in the last row in the classroom. As this continued, I became to be known as “a big pupil” by everybody in the school and this eased the relationship between me and the pupils in and outside the classroom. Much as my presence attracted attention from the pupils during my first days of participant observation, they eventually became used to me.

During short breaks and lunch time, I would play the pupils’ games together with them such as football with the boys and handball with the girls. This further helped the pupils become comfortable around me and this eased my process of information gathering because they could discuss with me freely without fear. In some ways, my data collection methods can be qualified as overt participant observation in natural settings (Cohen et al., 2007, p.398). This is because, during the entire process, much as the rest of the pupils in the school were convinced that I was a fellow pupil like them, my seven participants knew that I was a research student and we agreed together that this should remain a secret between them and me alone. Thus, to some extent, I was both a covert and an overt researcher (Bryman, 2008). My covert position could be ethically questionable if I had applied it to my research participants; but it can be argued that the covert element in this situation is not really ethically questionable because my activities do not affect the rest of the pupils in the school to whom I have decided not to declare the purpose of my presence among them. As Bryman (2004, p.302) observed, in participant observation, the members of the social setting are aware of the researcher’s presence and as such, some of my participants particularly in the first days of the data collection could pay more attention to me than to the teacher. This changed, though, in the following few days as I tried to adapt to their activities and tried as much as possible to show them that I was not unique or special and therefore not deserving special attention. This first stage of the data collection process was then followed by interviews.

### 2.3.2.2. *Semi-structured interviews*

I mainly used semi-structured interviews to collect data from my participants. I conducted individual interviews with seven HIV/AIDS orphans, five teachers, two senior women teachers, two Head teachers, one deputy Head teacher, five project officers, three project coordinators and three directors, one head of department, three caretakers/guardians/elders and two religious leaders. All these interviews are regarded as formal since they are arranged in advance with respect to time and place. Furthermore, the semi-structured interview is:

neither an open conversation nor a highly structured questionnaire. It is conducted according to an interview guide that focuses on certain themes and that may include suggested questions (Kvale 1996, p.27).

I had to use different interview guides for HIV/AIDS orphans, teachers, religious leaders, directors and project officers and the project coordinators since the kind of information I needed from these different groups of participants was not completely the same, though all were intended for enlightening similar themes related to the objectives of the study. All my participants approved the use of the digital recorder though I was not able to use it in one interview when I chose not to carry it with me due to the on-coming rain. On this occasion, I therefore chose to do note taking, which was not convenient as it tended to interrupt the discussion between myself and the interviewee.

The use of semi-structured interviews, which included open ended questions, was important in that it opened up for the emergence of information and statements that I had not anticipated. This makes it a quite convenient and flexible method of data collection as it tends to generate substantial amounts of useful data. Furthermore, this flexibility accommodated the involvement of different stakeholders in the community, as participants who fed me with different perspectives on the education related challenges and coping strategies. Thus, its loose structure was a strength of the use of semi-structured interviews as a method for data collection.

Much as finding a convenient quiet and safe place for conducting these interviews proved a little bit challenging, I must strongly acknowledge the efforts of the administrations of the two schools who worked very hard to secure locations which were free from excessive noise. One of the schools decided that I should use the school library particularly in times when the rest of the pupils were not using it and the other school located a room which is a short walk

away from the school premises was made available. This room was formerly used as a store but since the world food programme stopped bringing food to the schools from the beginning of this academic year (February 2010), it had since then been put to alternative use and conducting of this interview in it became one of the alternative uses. With the teachers, we used both the school library and the cool shades of the mango trees depending on the teachers' interest. Interviews with all directors, project coordinators and project officers were conducted in their offices, while for the religious leaders they were either conducted at their homes, the mosques or the churches. This all really depended on the convenience of the location to my participant. I deliberately decided not to make any decision on the location for conducting the interviews, and instead gave suggestions on the characteristics of a convenient place for conducting the interviews and this worked to my advantage. In addition, secondary data supplemented the information I collected through participant observation and interviews, which is briefly discussed in the next section.

#### 2.3.2.3. *Document analysis*

This data collection method has been used to gather information regarding how HIV/AIDS orphans are addressed in policy documents related to education. Information regarding current HIV/AIDS prevalence in the Sudan and the current number of HIV/AIDS orphans in South Sudan has also been obtained through this method. The analysis has been brief, according to the limited information regarding my target group. The documents that have been used are GoSS (2008) HIV/AIDS policy Juba; UNGASS (2010), Progress report (2008-2009); SSAC (2009), OVC Needs assessment, Kajo-keji. All these documents collectively helped to give me an over view on the government's policy on the education of HIV/AIDS orphans and the current number of HIV/AIDS orphans in South Sudan. The kind of data acquired from these documents was so rich that it formed the basis of the introductory chapter to this thesis

#### 2.3.3. **C. Data analysis**

Data analysis involves organising, accounting for and explaining the data; in short, making sense of the data in terms of participants' definitions of the situation, noting patterns, themes, categories and regularities (Cohen et al 2007, p.184). In other words, it is a systematic search for meaning and it is a way to process qualitative data so that what has been learned can be communicated to others (Hatch, 2002, p.148). Hammersley & Atkinson (2007,p.162) argued that the task of analysing qualitative data is to find some concepts that help us to make sense

of what is going on in the research situation. In line with this, interpretation analysis and writing were then used to analyse the data collected from the interviews. According to (Gall et al 1996, p.562), interpretation analysis refers to the process of examining research data closely in order to find constructs, themes and patterns that could be used to describe and explain the phenomenon being studied. In reference to this study, the phenomenon refers to the education related challenges facing HIV/AIDS orphans. This means that the analysis should enable me to make sense of the data, note patterns, categories and themes, and develop possible explanations and see which theories can be used to analyse the data.

Similarly, as will also be argued later, writing was used as a method of data analysis along with coding, sorting and categorization of data (Richardson & St. Pierre, 2000, p.970). That is, like Richardson & St. Pierre, I used writing as a method of data analysis. More specifically, writing especially the narratives of the findings and analysis chapter was used for thinking and drawing connections between the different concepts which emerged. Therefore, as Richardson & St. Pierre, (2000), argue, the process of data analysis in this study was not limited only to the conventional practices such as coding data and sorting it into categories and grouping the categories into themes that then became section headings. Thought happened in the writing process. “As I wrote, I watched word after word appear on the computer screen. All I see are ideas I had not thought of before I wrote” (Richardson & St. Pierre, 2000, p.970).

Furthermore, as Cohen et al (2007) argued, in qualitative research, data analysis commences during the data collection process and this, according to these authors, is because of both practical and theoretical reasons. At practical level, as my experience in the field has shown, qualitative research rapidly amasses huge amounts of data, and early analysis reduces the problem of data overload by selecting out significant features for future focus. Therefore, as the data collection process was still continuing, analysis was already being done, though it ought to be noted that this was still a preliminary analysis because thorough analysis of all the collected data took place in October, after all the data had been collected and transcribed. At this later level of the analysis, concrete themes were then built as I had to merge some of the categories which are related to build up the main themes.

While at theoretical level, analysis commences early on in the data collection process so that theory generation can be undertaken considering the fact that in qualitative research, theory is generated from the data. LeCompte and Preissle (1993, pp.237-53 in Cohen et al 2007)



advise that, in the theory building process, researchers should set out the main outlines of the phenomena that are under investigation, assemble chunks or groups of the data and then put them together to make a concrete whole. The intention of this, according to these authors is to enable the researcher to move from description to explanation and theory generation (Cohen et al 2007). Though this study has not generated a theory at this level, the concepts generated could be used as a basis for understanding some aspects of orphans' situations and behaviour.

#### **2.4. Narrative elements of ethnography**

Ethnography involves an ongoing attempt to place specific encounters, events and understandings in to a fuller, more meaningful context (Tedlock, 2000). Since it is an ongoing process, Tedlock, (2000) argues that, the writing of an ethnography is a “continuation of field-work, rather than a transparent record of past experiences in the field” (p. 455). This implies that, ethnography continues into the writing up phase of the study. This study, which involves strongly ethnographic elements, is an attempt to place my encounters with and understanding of the situation of the HIV/AIDS orphans in to a more meaningful context for easy accessibility by especially people who might not have had similar encounters with this group before. As Ellis & Bochner (2000); Tedlock and Richardson & St.Pierre (2000) have argued, much of the ethnographic work lies in the output or the written work. This is because after an ethnographer has accomplished the first part of the study which is fieldwork data collection, the successive stages of data analysis involves intensive writing until the final piece of work is produced.

Denzin & Lincoln (2005) asserts that, qualitative ethnographic research is endlessly creative and interpretive. The researcher does not leave the field with mountains of empirical materials and then easily writes up his or her findings. “Qualitative interpretations are constructed” (p.26). The researcher first creates some field notes, or what Sanjek (1990, p.386 in Denzin & Lincoln, 2005, p.26) calls “indexing”. This could be followed by the creation of categories that Denzin & Lincoln, 2005, p.26) refer to as “research text” .What may follow next is the final stage which is building of themes and producing of the public text that comes to the reader (Denzin & Lincoln, 2005). The foregoing processes imply that, the ethnographic researcher starts the process of interpretation and analysis of his or her data right from the field and continues with it throughout the writing process. As St. Pierre further asserts, “Writing is thinking, writing is analysis, writing is indeed a seductive and tangled method of discovery” (Richardson & St. Pierre, 2000, p. 967). Therefore, writing is used as a

method of inquiry; and a condition of possibility for producing different knowledge and producing knowledge differently (St Pierre, 1997b, p. 175 in Richardson & St. Pierre, 2000, p.969).

Turning to narrative ethnography Tedlock (1991, p.78 in Ellis and Bochner, 2000, p.741) argues that, this is where the ethnographer's experiences are incorporated into the ethnographic description and analysis of others. Here the emphasis is on the ethnographic dialogue or encounter between the narrator and members of the group being studied. Ellis and Bochner (2000) argue that, within narrative ethnography participants are encouraged to participate in a personal relationship with the researcher, to be treated as co researchers, to share authority, and to author their own lives in their own voices.

Moreover, readers, too, take a more active role as they are invited into the author's world, evoked to a feeling level about the events being described, and stimulated to use what they learn to reflect on, understand and cope with their own lives. Though this study uses a variety of elements of ethnography, the main aspects of narrative ethnography, like incorporation of the ethnographers' experiences into the ethnographic description and analysis feature prominently in the later chapters of this thesis, particularly Chapters three and four which present the findings and discussion of the study.

Now, we turn to narrative writing. Richardson and St. Pierre call this style of ethnographic writing creative analytical processes (CAP) referring to a writing style where the "author has moved outside conventional social scientific writing" (Richardson & St. Pierre, 2000, p. 962). CAP ethnography displays the writing process and the writing product as deeply intertwined; both are privileged. The product cannot be separated from the producer, the mode of production or the method of knowing (p.962). In their critique of the conventional criteria for assessing quality in qualitative research, like reliability and validity, Richardson & St. Pierre (2000) claim that, writing offers more possibilities because it is always partial, local and situational and that our selves are always present, no matter how hard we try to suppress them. They claim that working from that premise frees us to write material in a variety of ways. To tell and retell (p. 962). There is no such a thing like "getting it right" only "getting it" differently (Richardson & St. Pierre, 2000, p. 962).

Closely connected to narrative writing is reflexive writing. According to Trubshaw, (2003), reflexive writing is a research technique, in which the researcher combines his/her own

personal experience with critical thought and observation in order to develop a more complete and engaging analysis of an experience. This style of writing concerns the writer's feelings too (Trubshaw, 2003, p.1). It enables the writer to express a critical awareness of how he or she was writing about the participants of the study. As a reflexive writer and a researcher, I constantly reflect upon my personal experience while interacting with the HIV/AIDS orphans during the course of the study. Some of these reflections generate emotional feelings in me, particularly when I reflect on the conditions of the orphans as I witness some crying as they are being chased home from school for having not paid their school fees. However, I try to direct these feelings so that they affect my understanding and analysis of the situation in a productive way. By keeping some emotional distance, I was able to offer more appropriate assistance to my participants, hence contributing positively to shaping their schooling experiences. I address some of these issues in detail in the findings and discussion chapter, however, they do require some reflection from a methodological perspective and that is what the next section discusses.

## **2.5. Reflexivity**

According to Bryman (2008), reflexivity refers to a reflectiveness among social researchers about the implications for the knowledge of the social world they generate of their methods, values, biases, decisions and mere presence in the very situations they investigate (Bryman, 2008, p.698). Relatedly, reflexivity entails sensitivity to the researcher's cultural, political and social context (Patton, 2002, p.65). As such, 'knowledge' from a reflexive position is always a reflection of a researcher's location in time and social space (Bryman, 2008, p.682). Moreover, (Guba and Lincoln, 1981 in Denzin and Lincoln, 2000) puts the definition of reflexivity even more clearly by arguing that, reflexivity is the process of reflecting critically on the self as a researcher and the "human as instrument" (Guba & Lincoln, 1981 in Denzin and Lincoln, 2000, p.183). It is a critical subjectivity and more so, it is a conscious experiencing of the self as both an inquirer and respondent, as teacher and learner, as the one coming to know the self within the process of research itself (Denzin and Lincoln, 2000, p.183). They further argued that reflexivity forces us to come to terms not only with our choice of research problem and with those with whom we engage in the research process, but with ourselves and with the multiple identities that represent the fluid self in the research setting (Alcoff & Potter, 1993 in Denzin and Lincoln, 2000).

In reference to the foregoing, the researcher needs to demonstrate that he or she is part and parcel of the construction of knowledge. Therefore, the researcher is viewed as someone who constructs knowledge through observations and conversations with others and then often assumes control of presenting this knowledge to an audience. In reference to this study, my observation of the orphans as well as my conversation with them was an act of knowledge construction. Moreover, through the use of narrative ethnography, the participants in the study became part of the representation process that is also personal. As Ellis & Bochner (2000), argued, narrative ethnography encourages participants to participate in a personal relationship with the researcher in addition to making them author their own lives in their own voices (p.742). These interactions and relationships between the researcher and the participants in the process of creating knowledge require careful reflection. However, Lynch (2000) argues that the term reflexivity is a slippery concept because of two major reasons. One is that the term has different meanings and second is the assumption that a reflexive position is somehow superior to an unreflexive one (Lynch, 2000, cited in Bryman 2008, p.683).

Though Lynch is right in his arguments that the term reflexivity has different meanings, Hammersley & Atkinson's' definition of reflexivity does not differ much from that of Bryman. For example, they define reflexivity as the extent to which a researcher is being aware of his own values, ideas and prejudgements (Hammersley & Atkinson, 1995). It can therefore be argued that, reflexivity refers to the act of constantly reflecting on ones thoughts and actions to help one guard against them in affecting the outcome of the study in ways that are not accounted for.

Furthermore, it has been argued that the credibility of research findings is likely to be strengthened if a researcher openly and explicitly discusses his/her presuppositions and acknowledges his/her subjective judgements (Ashworth, 1997). This implies that reflexivity entails self- awareness and critical self –reflection by a researcher on his/her personal biases and predispositions as this may affect the research process and conclusion. This self-awareness helps a researcher to maintain openness to the context that is being investigated. Moreover, not only is there personal reflexivity, but there is also interpersonal and collective reflexivity too (Chiu, 2006, in Botha, 2010). According to Nicholls (2009) interpersonal reflexivity focuses on an evaluation of interpersonal encounters and the researcher's ability to collaborate with others (Nicholls, 2009, 122), while collective reflexivity on the other hand

demands the question of asking about the process of how the collaboration determined the frames of inquiry. It also asks what the terms of participation were, who participated or did not and what effects did this have on the outcome of social change and practical knowing for the community participants (Nicholls, 2009).

Therefore, throughout the course of this study, an attempt was made to be conscious of, aware of and reflect on my actions, interactions and roles in order to understand the effect I had on the data in the whole process of the study. Considering the fact that I am in some ways an insider because I grew up in the area and socialised within the local culture where this study was conducted, it is possible that my personal subjective judgements might have played a role in the process of conducting this study. This obliges me to acknowledge the impact that my personal subjective judgements might have had on the validity of this study.

However, it is important to note that despite being an insider, I kept an open mind to listen to the views and experiences of my participants and tried as much as I could to ensure that information gathered was not distorted. To ensure this, I had to ensure that the data collected was transcribed slowly and with care making the best use of the pause function in my digital recorder and making sure that I reflect critically on every transcript before beginning to transcribe the next interview. This is done in order to maintain a close relationship between my recorded data and the transcripts. As Kvale & Brinkmann, (2009) argued, both the recorded data and the transcripts are narratives, but overall a transcript is a translation from one narrative mode, that is to say the oral discourse into another narrative mode, namely the written discourse (Kvale & Brinkmann, 2009, p.178). This translation has implications for the knowledge making process.

### **2.5.1. Sensitive research and researching with the vulnerable**

It is practically difficult to divorce the concept of ‘sensitive research’ when one is conducting a study with the vulnerable. As a point of departure, it is worth explaining what is meant by ‘sensitive research’. To begin with, research is deemed as sensitive if it requires disclosure of behaviours, attitudes or conditions which would normally be kept private and personal and which might result in offence or lead to social censure or disapproval or which might cause the respondent discomfort to express (Wellings et al, 2000, p. 256 in Liamputtong, 2007). In this sense, Liamputtong argues that research into topics like illness status (particularly stigmatised diseases like schizophrenia, bulimia, anorexia and HIV/AIDS) may be among the topics of sensitive research.

Campbell (2002,p.53 in Liamputtong, 2007) contends that sensitive topics would be often the “ difficult” topics like trauma, abuse, death, illness, health problems, violence and crime that spawn reflections on the role of emotions in research. Lee (1993, p.5) suggest that sensitive research stretches beyond the consequences of carrying out the research; but methodological issues are also inherently essential in doing such research. While Liamputtong argues that issues like miscarriage, abortion, exploitation of the marginalised, the critically ill, being old and children who work as prostitutes are part of the topics regarded as sensitive research. However, for this study, I limit the definition of sensitive research to the study of people both infected and affected by HIV/AIDS considering the burden of stigma and discrimination this group of people carry in south Sudan.

However, who is a ‘vulnerable’ person and what does the term vulnerable really mean? It is important to note from the onset that a precise definition of the term ‘vulnerable’ is problematic as the concept is socially constructed. This said, it is then necessary to present a few definitions of the term from the perspectives of different scholars who have attempted to explain what the term means. Moore & Miller, (1999, p.1034 in Liamputtong, 2007) explained that vulnerable individuals are people who ‘lack the ability to make personal life choices and personal decisions to maintain independence and to self-determine’; meaning that vulnerable individuals may ‘experience real or potential harm and require special safeguards to ensure that their welfare and rights are protected’ (Liamputtong, 2007, p.2).

According to Stone (2003, p. 149), the ‘vulnerable’ are those who are ‘likely to be susceptible to coercive or undue influence’. He further explained that the ‘vulnerable’ include children, pregnant women, mentally disabled persons and those who are ‘economically or educationally disadvantaged’ (Stone, 2003, p.149). Liamputtong, (2007) further reinforced Stone’s definition by explaining that, the vulnerable include those who are affected by stigmatised diseases such as mental illness and HIV/AIDS. In agreement with Stone, Punch (2002, p. 323) suggest that children are particularly vulnerable in society, especially when their situation involves abusive behaviour on the part of adults in their lives. I argue that, in this regard, the definition is particularly applicable to the children who form part of this study. It was found that most of the HIV/AIDS orphans have been abused and some are still going through abusive experiences from adults in the communities in which they live. For example, many have been chased away from home, overworked, underfed and have their right to education denied.

The issues raised in the foregoing discussion make conducting research with the vulnerable as one of the most sensitive areas of study in the social sciences and that explains why conducting any research with the vulnerable requires the researcher to be sensitive. In line with this, it is worth noting that the goal of research with the vulnerable is that of discerning and uncovering hidden information about peoples' lives and experiences, information that has been hidden, inaccessible, suppressed, distorted, misunderstood and ignored ( Dubois, 1985 in Liamputtong, 2007). More so, it has become almost inevitable in the present climate of our fractured world that sensitive researchers will have to engage with the vulnerable, disadvantaged and marginalised groups as it is likely that these population groups will be confronted with more and more problems to their health and well-being (ibid).

Stone (2003) further argues that these groups of people are often hard to reach because in most cases, they are silent, the hidden...the marginalised and hence invisible populations in society. The reasons for their invisibility are many and may include their marginality, lack of opportunity to voice their concerns, fear of their identity, being disrespected, the stigma attached to their social conditions, and heavy responsibilities (Weston, 2004; Benoit, 2005; Fisher and Ragsdale, 2005 in Liamputtong, 2007). As will be evident in the structure of my findings chapter, I try to address this voicelessness primarily through narratives.

The methodological issues hinted by Lee above mainly focuses on moral and ethical issues involved while conducting research with the vulnerable, such as, issues to do with informed consent, confidentiality and safety of the participants. A brief discussion on these issues will be undertaken in this first part of the section, as the same issues will be discussed in detail in the last part of this section where I will focus more on the ethical considerations undertaken in the field with my participants while collecting the data.

There are some debates about moral issues regarding research with vulnerable people. For example, should researchers carry out investigative work with some extremely vulnerable populations such as frail or elderly people, people suffering from mental illness, HIV/AIDS and those affected by these diseases? As Hallowell (2005, p.149 in Liamputtong, 2007) acknowledges, "as researchers (and human beings), we act as 'morally responsible selves'...- we need to be flexible and reactive, but above all, accountable for our actions". Ultimately, the aspects of flexibility and accountability expressed in this quote are very important for any individual conducting research with the vulnerable. More so, as sensitive researchers, all our work with the vulnerable should be aimed at improving their lives. As such, we should be

able to make it known to all those we are studying what information we need from them and why we need such information.

Confidentiality is one of the most important aspects to be taken care of while conducting research in social sciences in general but with the vulnerable in particular. The confidential nature of research may permit the vulnerable people to open up and reveal their concerns. Additionally for some, participating in research provides them with a therapeutic experience (Hess, 2006 in Liamputtong, 2007) and in some cases, it is empowering (Campbell, 2002; Rickard, 2003 in Liamputtong, 2007). Moreover it also makes them feel that “at least some one is listening to their vulnerable stories” (Liamputtong, 2007, p.29).

Ethical issues are hard to neglect when conducting research with the vulnerable. In most cases, conducting research on vulnerable people raises numerous ethical issues and these normally require careful consideration. Hence, discussions around the ethics of bringing people through painful experiences are essential. In regards to this, it is argued that, sensitive researchers must carefully manage the emotions of the participants and ensure that by participating in their studies, the vulnerable research participants are not left with painful experiences (Liamputtong, 2007). Dickson-Swift (2005) further warns that, although ethical issues are important, sensitive researchers must be more cautious about the confidentiality, privacy and anonymity of their participants and as Flaskerud and Winslow (1998, p.10) clearly put it:

Research with vulnerable populations challenges us to consider once again ethical principles basic to research. Issues of providing informed consent, maintaining confidentiality and privacy, weighing the risks and benefits of a study, and paying attention to issues of fairness are all especially important when working with groups who are vulnerable.

Regarding the safety of our research participants, Liamputtong (2007) argued that, we must ensure that our participants will not be adversely affected by participating in our research. Melrose (2002, p.343 in Liamputtong, 2007) too contends that researchers have a duty to ensure that no harm comes to their participants, whatever their ages, as a result of their agreement to participate in research. If we cannot guarantee that such participation may improve their lives, we must ensure, at least, that our scrutiny of them does not leave them worse off.



Thus, when doing research with the vulnerable, the ethical choices we make as researchers should be motivated by an underlying morality (for example, a desire to: respect and care for others; promote justice and equality: protect others' freedom and avoiding harming others), which guide our behaviour, not just during the course of our research, but in all of our social interactions (Hallowell et al.2005, p.149 in Liamputtong 2007, p.45). As indicated earlier, the last part of this section focuses more on some of the ethical considerations undertaken in the field with my participants while collecting the data.

Therefore ethical considerations play a significant role in the success of any research project and the purpose of an interview investigation should be out of respect to the improvement of the human situation being examined. This therefore means that one has to continue making ethical considerations throughout the research process (Kvale 2009). Furthermore, as Scheyvens and Murray (2003) argued, "...while truth is good, respect for human dignity is even better" (Scheyvens and Murray, 2003:158). This argument seems to suggest that, a researcher should try as much as possible to keep any information obtained from the participants during the course of the interviews confidential. This is to avoid causing embarrassment and harm to ones' participants. As Buchanan, (2009), contends, "One major threat of harm lies in the embarrassment or stigma to the individual that may result from disclosure of personal information" (Buchanan, 2009, p.8). This implies that a social researcher is obliged not to disclose any confidential information revealed to him /her during the interview by a research participant to a third party.

Related to the afore mentioned, my study deals with a very sensitive topic. Usually, HIV/AIDS and orphans are not easy topics to discuss. Taking this in mind, it was then important for me to stress the issue of "informed consent and confidentiality" (Kvale 1996, p.112) before engaging in interviews. This argument is in line with the ethical guidelines given by Bryman where he pointed out that "the social researcher should try to minimize disturbances both to the subjects and to the subjects' relationships with their environment" (Bryman, 2004, p.511). Therefore, in an attempt to follow this, I had to ensure that the prospective research participants were fully informed in advance of the purpose of the study and the procedure involved at the beginning of the interview. For the HIV/AIDS orphans, who were "double orphans", the consent of the caretakers/guardians and the school administration was obtained while for the "single orphans", the consent of the parents and the school administration was obtained since all of them were below the consent age of 18.

Another key issue to note is that no force was used on the participants to take part in the study. In addition, at the beginning of each interview, the participants were informed that they had the right to withdraw or be quiet during the interview at any time if they feel uncomfortable with the discussion or the questions being asked.

Importantly, Kvale (2006) reminds researchers that ethical issues do not belong to a separate stage of the interview investigations, but rather it is the entire part of the research process. In regards to this therefore, the issues of confidentiality were emphasised throughout the whole research process to all the participants. More so, participants were assured that pseudonyms will be used when referring to them in this research report and the use of these pseudonyms do not only apply to them alone, but to all the schools and institutions with which they are associated. Issues of credibility and trustworthiness are closely linked to ethical issues as elaborated above, and that is what the next section will focus on.

## ***2.6. Issues of credibility, trustworthiness and Authenticity***

For quite a long time, concepts such as reliability and validity have dominated the world of research. However, reliability and validity criteria for assessing quality in qualitative research are now changing as most qualitative researchers associate them to positivistic schools of thought (Guba & Lincoln, 2005). Instead, qualitative researchers have now adopted concepts such as trustworthiness and authenticity for assessing quality in qualitative research (Guba & Lincoln, 2005). Trustworthiness is made up of four criteria, each of which has an equivalent criterion in quantitative research. For instance, credibility parallels internal validity; transferability parallels external validity; dependability parallels reliability and confirmability parallels objectivity. I will focus much of my discussion on credibility as one of the important criterion of trustworthiness in qualitative research study.

### ***2.6.1. Credibility/Validity***

Guba & Lincoln (2005) argue that, ensuring credibility is one of the most important factors in establishing trustworthiness in a qualitative research study. Similarly, many academic scholars argue that the credibility of any academic research have to do with truthfulness of the data obtained and the Knowledge of the researcher in interpreting the collected data. Bryman (2008) argues that, the establishment of the credibility of findings entails both ensuring that research is carried out according to the canons of good practice and submitting the research findings to the members of the social world who were studied for confirmation that the investigator has correctly understood that social world (Bryman, 2008, p.377).

This technique which is often referred to as respondent validation or member validation is a very important criterion for assessing the credibility of a qualitative research study. For this study particularly, respondent validation was one of the techniques used for assessing its credibility. This was done by discussing my preliminary transcripts and analysis with my primary informants to find out whether they agree with what I have written down as their exact words. This exercise was done on a participant to participant basis and in some situations, the discussion called for a second round of interviews as well. Though this process is very tedious and demanding to the researcher, I believe it is a significant way of validating research information. Issues of power relations between the researcher and some of the participants were evident during this exercise. This needed to be appropriately handled by the researcher in a number of ways. Important in this regard is the good relationship I have developed with my participants. This reduced the inherent fear some of the participants have. As our relationship matured, the issues of power relations tended to naturally become less dominating and we started to relate more freely. As time went by, my newly acquired name of 'big pupil' during the field work became common almost to all pupils in the school. In addition to the good relationship built, I constantly encouraged my participants to openly communicate with me and comment on any issue they were not satisfied with without fear. Therefore, among others, these two approaches I developed helped me in achieving my aim of validating my data with my participants, hence contributing to the credibility of the findings.

Furthermore, it is not only the use of respondent validation that accounted for the validity in this study, but also interpretation. This is because validity is closely linked to interpretation (Kvale, 1996). These interpretation issues strongly apply to the interpretation of the interview questions asked by the researcher. They could also apply to the researcher's interpretation of the respondents' answers. Another way of ensuring validity in this study was thus by ensuring that the questions and statements were made very clear and easy to understand, and, that ambiguous words were avoided as much as possible. More so, questions in my interview guide also necessitated thorough preparation before the actual start of the interview process. To achieve this, various sources from my "community of practice" such as my supervisor and some of my lecturers helped me in proof reading the questions. In addition, while preparing to conduct the interviews, I had to take into consideration Kvale's advise to all researchers that to ensure credibility of the subject's responses, the researcher can ask follow up and

clarifying questions or repeating the answer and saying ‘do you really mean that’ or is that what you are saying?’”(Kvale, 1996, p.217-243).

Closely connected to the issues of credibility/validity discussed above is the concept of triangulation which tries to show that the validity of a given study can be achieved by use of more than one method for data collection (Bryman, 2008; Patton, 2002). Richardson and St. Pierre (2000) dispute the usefulness of the concept of triangulation, which is the simultaneous display of multiple, refracted realities (Denzin & Lincoln, 2005, p.6), asserting that the central image for qualitative inquiry should be “the crystal, not the triangle” (p. 6). They assert that crystals are a more appropriate metaphor for validity in qualitative research because crystals grow, change and alter. They are prisms that reflect externalities and refract within themselves, creating different colours, patterns, arrays, casting off in different directions (Richardson, 2000, p.934). They argued that, in the crystallization process, the writer tells the same tale from different points of view. In the case of the stories of the HIV/AIDS orphans related to the education challenges they face and the coping strategies they developed, the stories are presented from their point of view, as well as the researchers’ point of view. These different representations, I argue enables the text to validate itself through the depth of the information it provides. As Richardson & St. Pierre assert, crystallisation, without losing structure, deconstructs the traditional idea of “validity”. “We feel how there is no single truth, and we see how texts validate themselves (p.963). To them, crystallisation provides us with a deepened, complex, and thoroughly partial understanding of the topic (Richardson & St. Pierre, 2000, p.963). If we accept that there is no one “correct” telling of an event (Denzin & Lincoln, 2005, p.6) then each telling, like light hitting a crystal, reflects a different perspective on the same incident (p.6). This discussion on triangulation also leads us to the authenticity concept.

### ***2.6.2. Authenticity in qualitative research***

Authenticity is the degree to which one is true to one's own personality, spirit, or character (Wood; Linley; Maltby & Balious; Joseph, 2008).The aspect of truth is very important in this definition. It seems to suggest that, for any research findings to be seen as authentic, it has to bear some truth. Guba & Lincoln (2005) moved a step further and developed some authenticity criteria which they believed are “hallmarks of authentic, rigorous, or “valid” constructivist or phenomenological inquiry” (Guba & Lincoln, 2005, p.207). These are “fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical

authenticity” (Guba & Lincoln, 1989, p.245-251 in Guba & Lincoln, 2005, p.207). However, relevant to this study is the authenticity criterion of fairness as the other criteria such as ontological and educative authenticity were designed as criteria for determining a raised level of awareness by individual research participants and catalytic and tactical authenticities refer to the ability of a given inquiry to prompt, first, action on the part of research participants and, second, the involvement of the researcher in training participants in specific forms of social and political action. Hence, these latter categories are not relevant to the focus of this study which interest is in exploring the challenges and coping strategies of orphan children.

Fairness, though, is thought to be a quality of balance. Its emphasise is that all stake-holders views, perspectives, claims, concerns, and voices should be apparent in the text (Guba & Lincoln, 2005). As will be evidenced in the findings chapter, most of the stake-holders such as elders, teachers, religious leaders ,government officials and NGO staff who directly work with the orphans have had their voices, views and concerns represented in the text or the findings of this study as required by this criterion. More so, the most important stake-holders in the study, that is the HIV/AIDS orphans have significant representation of their views too. As Guba & Lincoln, (2005) argued, omission of stake-holders or participants’ voices reflect a form of bias to a large extent. They further explain that, the bias referred to here is not related directly to the concerns of objectivity that flow from positivist inquiry and that are reflective of inquirer blindness or subjectivity. Rather, this bias counters the kind of fairness defined by deliberate attempts to prevent marginalisation, to act affirmatively with respect to inclusion, and to act with energy to ensure that all voices in the inquiry effort had a chance to be represented in any texts and to have their stories treated fairly and with balance (Guba & Lincoln, 2005). As has been hinted earlier in this section, the purpose of adopting narrative form of presenting the data of this study is to promote this authenticity criterion of fairness to the research participants. This is intended to give an opportunity for most of the stories of the HIV/AIDS orphans related to the education related challenges they face to be presented with minimal distortion and the stakeholders working with them to be represented in the text or the research report with a balance. That is not to say that this study is without its challenges and limitations. We now turn to reflect about some of the challenges faced in the course of this study.

## **2.7. Challenges and limitations of the study**

### ***2.7.1 Pragmatic and logistical challenges encountered in the field***

Though there are many advantages associated with conducting a field study in one's home area, like one's familiarity with most of the stakeholders and with the area as a whole, the fact that one is conducting the study as an insider makes it quite difficult to rule out challenges. In the first place, many people in the area knew me as an NGO staff member and the common belief in the locality is that NGO staff are fairly well off financially considering the fact that the salaries of most NGO staff are high compared to other civil servants and more to that, they are paid promptly. Secondly, the fact that I had just returned home from schooling in a European university is enough reason for many to think that I had a lot of money for supporting them, particularly the needy and of course, some of my participants cannot be ruled out from the list of those having high financial expectations in me. As I have presented in my findings chapter, just in the second week of my participant observation in one of the schools, one of the HIV/AIDS orphans ran to me as I was on my way home and presented to me a challenge she faces of a broken shoe with a hope that I might be able to offer a solution.

Closely connected to the above were the expectations from some of the teachers, care takers, religious leaders and the other stakeholders I interviewed. Much as I had stated the objectives of my study to them very clearly and had told them that the data I was collecting was purely for academic purposes, I was still getting comments such as: "If you finish and this project succeeds, don't forget me." Another remark was: "It is good that you a writing a project about the orphans. This will help them to get scholarships when you get some funding." Yet another comment was from one of the coordinators requesting that a hall be constructed for them for conducting activities like meetings, dramas etcetera. From these remarks, it is easy for one to see that the purpose of the study is being misunderstood by some sections of my participants, hence presenting a challenge to me in terms of negotiating a balance between achievements of the objectives of the study and addressing the expectations of my participants.

Furthermore, although most of my participants were cooperative, a few were unreliable and even dishonest when it came to keeping appointments for interviews. The avoidance practice of "come tomorrow, that is when I have free time" was common with some officials and it was even worst when it came to telephone appointments. One example is particularly

revealing. We had agreed to meet on a Wednesday with one of my to be participants. However, before I started off from home, I decided to find out if I would get this official in the office at the agreed time. The feedback I got was that; “Ohhhh sorry, today am not in office. I have been urgently required to go to the field and as I talk with you now, I am actually on my way”. I was frustrated because I badly needed some data from the South Sudan AIDS Commission office in Juba and because that was my second last day in Juba, I decided to go to the SSAC office with a hope of interviewing anyone I will find cooperative, or request for any literature regarding HIV/AIDS in South Sudan since I had to hurry back to Kajo-keji to conduct my second round of interviews and do data validation with those I had interviewed earlier. Upon reaching the SSAC office, I could hardly believe my eyes when I found the very official who had told me he was on his way to the field, comfortably seated in the office. I remained calm, and even though I didn’t succeed in interviewing him or any other official at SSAC at GOSS level, I did succeed in obtaining some very important documents.

Closely connected to the above is the challenge of rough roads and inadequate transport from Kajo-keji to Juba. I had to cancel my journey to Juba for my data collection several times until one day when luck was on my side and I happened to meet one of the high level officers in the army working in Juba. He offered me a ride in his vehicle although not directly to Juba. I had to travel through Yei which presented no problems since it is possible to find public transport from Yei to Juba on daily basis. These challenges show that, a researcher often has to deal with situations that are unplanned and therefore should be aware that all kinds of skills and good fortune shape the research process. The last part of this chapter highlights some of the limitations of the study.

### **2.7.2 *Limitations of the study***

This study has a number of limitations of which some need to be mentioned and explained briefly. To begin with, since the study employed purposive sampling, its findings cannot be generalised to greater contexts. As other qualitative researchers like LeCompte and Goetz (2008) have recognised, it is always very difficult to generalise in qualitative research as “it is impossible to ‘freeze’ a social setting and the circumstances of an initial study to make it replicable in another setting”(LeCompte & Goetz in Bryman, 2008, p.376).

Secondly, the study focused strictly on HIV/AIDS orphans, not orphans in general. This further limited the findings of the study to the education related challenges faced by

HIV/AIDS orphans only, not orphans in general, hence limiting my ability to understand the kind of challenges the orphans other than the HIV/AIDS orphans face. I suggest, this can be an area for further research. Closely related to the above is the fact that I have to limit my literature review strictly on HIV/AIDS orphans, leaving out a wealth of information regarding the challenges the other categories of orphans face. This in turn limited my understanding only to a specific category of orphans.

However, it is hoped that, the in-depth data collected from the multiple sources about the education-related challenges and coping strategies of orphan children in Kajo-keji County, South Sudan is seen as strength of this study so that this information could be useful to policy makers and researchers in the future.



## Chapter three: Findings

### 3.0. Introduction

This chapter is presented in various narrative forms and is built up of a collection of narratives related to the education related challenges and the coping strategies of HIV/AIDS orphans in South Sudan. The idea of putting all the findings of this study in form of narratives instead of using a conventional social scientific voice is to take the mind and the heart of the reader wherever he/she may be in the world right to South Sudan and share the world and the life experiences of the HIV/AIDS orphans through reading these stories I have presented. As Ellis and Bochner argue, this style of writing tries to protect the data from being “simplified, categorised, sliced and diced” (Ellis and Bochner in Denzin and Lincoln, 2000, p.737). They argue that:

narrative style of writing create the effect of reality, showing characteristics embedded in the complexities of lived moments of struggle, resisting the intrusion of chaos, disconnection, fragmentation, marginalisation and incoherence, trying to preserve or restore the continuity and coherence of life’s unity in the face of unexpected blows...(Ellis and Bochner in Denzin and Lincoln, 2000, p.744).

It is believed that, by presenting some of the data in form of stories, the reader may have an opportunity to listen fully to the voices of the HIV/AIDS orphans since one of the implicit objectives of this study is to give these vulnerable children a voice with which they can communicate about the education related challenges [or what Ellis & Bochner calls unexpected blows] they face and how they on their own are struggling in coping with these challenges.

As the available literature has shown, most of the studies about HIV/AIDS orphans have mainly been centring on the challenges they face (Ntozi,1997; Africa recovery, 2001; MRC Policy brief,2002; Atwine et al, 2005; Togom,2009 and UNGASS, 2010;) and how other stakeholders have contributed in helping with these challenges (Ntozi et al, 1995; Ntozi, 1997; Africa recovery, 2001; MRC Policy brief, 2002), while leaving out a very important part in the area of coping and particularly the struggles of the HIV/AIDS orphans in coping with their challenges; and that is the gap this study is intended to fill.

These stories have been created by drawing on the experiences which are common to the orphans. All the findings in this chapter have been presented in two main parts. The first part of the chapter presents stories/narratives related to the food, material, medical and financial

challenges the orphans face. The coping strategies they have developed in the face of these challenges have also been presented in this part. The second part of the chapter presents stories/narratives related to stigma and discrimination challenges at various levels of the society and how these negative experiences affect the lives and education of the HIV/AIDS orphans. The chapter is concluded by presenting a brief summary of all the food, medical, financial, material and emotional challenges faced by the orphans and the coping strategies they have developed.

### **3.1. Part 1: Financial & Material challenges and coping strategies**

#### **3.1.1. From home to school**

It is a typical Monday morning and the school week has started for Pitet, a sixteen year old girl who lost her mother and is busy losing her father as well due to HIV/AIDS. As usual, she begins the day with her domestic chores before going to school. Pitet gets up at 5:00 am in the morning, so that she can pick up her 20 litres jerry can and go to the borehole to fetch some water. Since the borehole is two kilometres from their home and she has to fetch two jerry cans of water every morning, she has to be sure to be running instead of walking. Once she is done with the water, she washes the dishes they had used the night before, sweeps the compound, washes her legs and off to school.

It is 7:50 am when Pitet arrives in school and is immediately arrested by the prefects on duty as a later comer. She has to go for slashing<sup>1</sup> in the football ground for 15 minutes as a punishment for coming late. At exactly 8:15 am, it is school assembly time and the teacher on duty arrives. “Good morning pupils” He greets, “Good morning sir” the pupils reply. “Today is Monday morning, the first day of the week and you all look very beautiful in your school uniform”! He continues: “Now, how many of you have come in non-school uniform or without shoes. “Silence... Everybody is very quiet because some of the pupils are not in school uniform and Pitet is one of them.” Now listen”, the teacher continues. “For those of you, who have come without school uniform for whatever reason, come to my office after the assembly for an explanation immediately”.

As soon as the assembly has finished, hesitantly, Pitet goes to the duty master’s office and explains to him that she does not have both the school uniform and the shoes because there is

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<sup>1</sup> Part of the manual work (cleaning compound) as part of skills training but mainly taken as punishment for late coming such that orphans’ attitude associated with it is negative

no money for buying them and there is nobody to help her either in kind or in cash. “Okay, I will give you one week to look for the money and buy the school uniform and the shoes over the weekend. By Monday, you should be in full school uniform. “Now go!” he ordered. Pitet quietly marches out of his office, totally confused because she doesn’t have any clue as to where and how to find the money for acquiring the above items.

After several hours of desperate thinking, she hits an idea. Fortunately enough, it is already mangoes season. Pitet spends her afternoon picking mangoes and selling them at the nearby market. With some good fortune, she is able to get 500 Uganda shillings from the sale of the mangoes. In the evening, she goes to her father’s room to ask him for some money for buying her school uniform, shoes and paraffin for studies. As though her request is an insult to him, the reply she gets is an angry one: “Are you laughing at me? Where do you think I can get the money? I suffered alone in looking for my school fees and the rest of the school materials when I was a pupil. You suffer the way I had suffered”

Frustrated and stressed, Pitet eventually comes up with two ideas. One is fetching water for sale. Since there are some construction workers working in the nearby centre, she asks them if she can fetch water and sell it to them. They accept and together, they agree that she can begin on Saturday of that same week. As she waits for Saturday, she implements her other idea of preparing and selling pancakes. From this enterprise, she gets 2000 Uganda shillings. That Saturday, she fetches up to 10 jerry cans of water and makes more than 3000 Uganda shillings. Though she is happy about this unexpected success in her struggle, still this money isn’t enough. It is only enough for buying the piece of the cloth for the uniform, but not sufficient for paying the labour cost of the tailor and for buying the shoes. She continues to work hard at selling mangoes and gets the required money for the labour cost by the end of that week. Finally, she has a school uniform, but that was not the end of the story. More challenges still lie ahead of her.

“My other challenge is now in buying the shoes” she explained and this was the day I met her. Just as I was on my way home, she ran to me, and this time, she didn’t call me by my newly acquired name of ‘Big pupil’. Instead, she called me teacher, and told me, “Teacher, you see, my shoe sole has already broken and I have no money for buying another one and our teachers chase me home if I come without shoes to school.” Because she wanted me to really see her broken shoe sole, she rose up her leg to show me the broken part which indeed I saw was badly broken. When I suggested to her that she should take the shoes to the shoe

repairer, she responded, “No sir, my shoe sole is already broken so bad that it cannot be repaired and more to that, I cannot afford the money for paying the labour cost of the shoe repairer”

In the second week, I met Pitet again for another interview and she continued with her story. She explained that, all her friends go home for their lunch every lunch time. As for her, she could run to the school borehole and take two cups of water to keep her strong to return to class. She also does the same during breakfast time. “Since our break time is in the early hours of the morning, I could take one cup of water to keep me strong until lunch time,” Pitet explained. She explained that, at first, she found it hard to adjust herself to going the entire day with water, but as of now, she is already used to:- “My only challenge in the course of the day is during the afternoon lessons. I always find it hard to see what the teacher writes on the chalk board and my head seems to be turning round and round. Sometimes I could not hear him well. This tends to affect my performance in the class because generally speaking, I cannot concentrate in the afternoon. Right from home to school, my life is a struggle”, she lamented, explaining that, when she returns home in the evening, another challenge awaits her...accommodation. She does not have her own room to sleep and study in. Their small kitchen which is used for cooking and is also the family store is where she sleeps. When it is time for studies in the evening, she has to go to her brothers’ room and share his lamp and in days he feels tired and does not want to study, she has to also go without studies.

The foregoing is a brief account of how Pitet, an HIV/AIDS orphan spends her day and week. Waking up very early in the morning and beginning the day with domestic chores and ending up reaching school late. And yet, life is not easy at school as she has to conform to the school requirements regardless of whether she can afford to or not. In short, the day to day life for this orphan is characterised by struggles for survival and taking absolute responsibility for meeting her personal and school needs. I want to point out here that Pitets’ account above is not an isolated incident. Overall, her story is a reflection of the life of many of the HIV/AIDS orphans in Kajo-keji County, South Sudan. This can be justified by the following examples of similar stories narrated to the researcher by some of the HIV/AIDS orphans.

I was in my third week of the interviews and had just completed interviewing one of the orphans. It was break time and the pupils were very happily playing and jumping here and there. But just as I was approaching the head teachers’ office, I saw Lomole in front of me already crying. I asked him what the problem was. “I have been chased home” was his reply

to me. Why? “That I have not yet paid my school fees”. I took him aside and consoled him until he stopped crying.

I was familiar with Lomole and knew that his do not end in the school. Another trouble awaits him at home and that is mainly caused by two or three things. One is his mothers’ absence from home, a second is a lack of food for him to eat, and yet money is another issue for him to battle with. Because of being overwhelmed by all these issues attacking him from all directions, he keeps crying most of the time which to me seems like a strategy he has developed for relieving himself from these negative emotions. As he shared his story with me during the interviews, the session was characterised by periodic crying and smiles and below is his story. I enquired from him whether the school sometimes excuses him if he delays in paying his school fees.

No, the school usually tells us: “You have not paid. Go and stay at home; and sometimes, they also warn me when I come without uniform. So I had to fetch water and sell then use the money for buying the uniform, even soap and all what I need. Even now the food we have is finished. So if we get 500 Uganda shilling (about ¼ USD), we use it for buying food. My mothers’ condition is even now bad because of the ulcers and the doctors advised her not to do heavy work like digging. But she tells us that she will do like that. If she will die, let her die (Lomole).

Before he finished narrating his story, tears started flowing from his eyes. I had to suspend the interview session in order to counsel him. Lomole’s experiences reminds me of the Zimbabwean orphans in Germann’s (2005) study who have to undergo similar experiences in their lonely lives.

On a negative note, the data collected for this study show that more HIV/AIDS orphans undergo similar experiences and in some instances, even worse. Yatet, a 15 year old orphan has to carry out all the family responsibilities of taking care of her siblings in addition to fetching water for sale and doing other income generating activities in order to earn a living. She started by telling me about the health condition of her mother, who is actually her only surviving parent.

*My mother is a bit ok but not really well. She suffers from typhoid and ulcers and the doctor even advised her not to dig, but she told us that she will continue digging like that. You know my mother tells me that she doesn’t want her children and herself to die of hunger and she has really become very, very thin. When I begin thinking about her, I could not concentrate in*

*school at all and maybe that is why I am always failing my tests and exercises in P.7 these days.*

*If only I had time to do some practice and revisions at home, maybe my results could improve a bit, but doing practice and revisions ended when my mother was still here. Actually, I must say that those days when our mother was here, I used to do practice, but now; I am not able to do so because as soon as I reach home, I have to cook for ourselves food and do all the domestic work since I am the only eldest person in the family and you know, sir, my performance is really becoming very bad. When my mother was still at home, I was performing well in school. But ever since she went to Umbuku and left me with my younger brothers, my performance in the class worsened because I have to do all the domestic work alone and also fetch water and move along the streets in Wudu<sup>2</sup> town in order to sell the water to the hotel operators. This really takes much of my time for studies.*

Yatet's situation, which is closely related to that of Pitet and Lomole, gives a clear picture of the plight of the HIV/AIDS orphans in Kajo-keji County, South Sudan. It is imaginable that the school performance of these HIV/AIDS orphans can hardly improve unless a helping hand is extended to them. As the majority of the orphans have stated, their ability to attend school regularly is badly affected, let alone the fact that some may be unable to enrol to school. In an attempt to reduce the plight of the HIV/AIDS orphans in South Sudan, IGAD in collaboration with the SSAC initiated a scholarship programme as a pilot project in Kajo-keji County. This money is channelled to the respective HIV/AIDS orphans in the various schools by KKLC, an association of people living with HIV/AIDS. The scholarship money is only enough to pay the school fees of 80 HIV/AIDS orphans out of 290 in Kajo-keji County alone, the site of this research project. In practice, this means that the orphans have to work harder to raise money for meeting some of their school needs. Other than the IGAD support to the HIV/AIDS orphans, the various religious institutions try to extend some support to the orphans too.

As the head of one of these institutions supporting the HIV/AIDS orphans explains: "The kind of support we give to them is by paying their school fees. That is the only support in terms of education we are offering to those few who have been selected" (Coordinator-Ayet).

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<sup>2</sup> The main town in Kajo-keji County where most of the trading activities take place

Apart from the financial support the heads of these institutions extend to the HIV/AIDS orphans, they also offer guidance and counselling services to them as well. For example, project coordinator-Nyadeng explained that, “when we go to visit them in the school, we encourage them that when they go home, they should not sit idle. They should be able to do some activities which can generate for them some bit of income for buying a piece of soap”. Similar roles are being played by other important stakeholders like Yaba, who heads an orphanage centre founded by the Christian community. He explained that:

In our attempt to improve the academic performance of the orphans, we had to organise some extra teaching for them. For example last year, we had what we call extra teaching basically for those orphans who are in p.5, 6 and 7 for one hour and we had teachers who teach them. We had also bought text books for all the subjects and created a small library and with the additional teaching, their performance has started to improve. Another strategy we have employed to make their performance improve is to organise for them to have evening studies; what is commonly referred to as “preps”. We do also offer both group and individual guidance and counselling services to them on regular basis.

The contribution of this orphanage centre to the well-being of the orphans is very significant. Through the financial support this orphanage centre gets from some of their partners abroad, the centre is able to accommodate over 100 orphans with different causes of orphanhood and provide for them some food, educational, health, including guidance and counselling, services.

Like the Christian community, the Muslim community also tries to support the HIV/AIDS orphans. A religious leader from this community explained that:

The HIV/AIDS orphans are really suffering and sometimes, they drop out from school because of inability to pay their school fees. So what we do as a mosque is to collect the little we have and apportion it to them because sometimes they do not get something to eat or even cloth to put on. The little we find, we apportion it among them because we are also powerless; Haza salaam aleikum (Religious leader-Salam).

When the call to Ramadan prayer got me in Kajo-keji, I also joined the rest of the Muslims in the prayer, and my presence at the mosque gave me an opportunity of seeing for myself what Salam explained above. After the prayers, the worshippers were asked to contribute whatever little they have for helping the orphans so that they can have a happy celebration of the Ramadan. About 20.000 Uganda shillings<sup>3</sup> were collected and all was apportioned to the

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<sup>3</sup> Ugandan shillings are a dominant currency used in Kajo-keji County because of the County’s proximity to Uganda. It is more preferred to the Sudanese pounds because most residents in Kajo-keji County buy goods

orphans who were present at the end of the prayers. My observation however is that, much as this assistance can provide a short term solution to the orphan's problems, it is like a drop in the ocean because there are only two of these holy days in the year and these are the only days the orphans get support from the mosque.

Institutions like the schools are not any different. Most of the staff I had interviewed in the two primary schools explained that the only support they can provide to the HIV/AIDS orphans is non-material. For example, guidance and counselling, when required and the knowledge and skills they impart to them. Other than these services, there is nothing much they can do because they live very difficult lives as well considering the low salary levels of the teachers in South Sudan coupled with the irregularities in the payment of the salaries (UNICEF/GoSS, 2008). For example, one teacher lamented:

I don't think I can help. There is nothing! The only assistance we give is only in terms of knowledge. If the child is weak, she is helped and if the child is also active, she is also helped. But in terms of materials, there is nothing. Teachers also here, we are getting very little pay as you know here, the cost of living is very high. We get very little and our life also, we are pushing rough. Here, a teacher works from morning to sunset, so you have to rely on that small budget. What we only do is the knowledge we are giving to them (Teacher-Lokutuk).

Most of the teachers interviewed presented similar arguments, and yet, these arguments are not any different from the ones presented by the religious leaders and the heads of the other institutions; meaning that if the HIV/AIDS orphans are to remain in school, they themselves have to develop appropriate strategies for coping with their challenges.

### **3.1.2. Coping strategies**

In reference to the fore going arguments, it is worth noting here that because of the limited support the respective stakeholders can provide, many HIV/AIDS orphans have been left unattended to and even those who are on scholarships have to struggle to meet some of their school needs as the scholarship is only meant to cover school fees costs. In an attempt to earn a living and remain in school, they have to engage themselves in doing income generating activities like fetching water for sale, selling mangoes, Pan Cakes, cassava flour, cowpeas leaves or doing leja-leja<sup>4</sup> generally. In addition, they have to look for alternatives of coping

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from Uganda and more to that, the Uganda currency has some smaller denominations as opposed to the Sudanese pounds.

<sup>4</sup> A common word across many Sudanese and African societies referring to any paid manual work/labour.



with their food and medical challenges. For example, all of them explained that they work in the family garden together with their guardians outside school hours. Meanwhile, the use of local herbs in times of illness has become an effective way of addressing their medical challenges since the local herbs are believed to be effective and yet costless. Below are some of their voices as they explain to me their experiences.

Sometimes I pick the leaves of cowpeas, take to the market, sell and use the money for buying the missing requirements. Other than selling the leaves of cowpeas, we sometimes pound dry cassava into flour and then take to the market and sell and then use the money for buying the missing school requirements. Sometimes if we are lucky we can get up to 1000 Uganda shillings per day (about 0.5 USD) from the sale of the cowpeas leaves, and for the pounded cassava we can get at times up to 2000 Uganda shillings (Busan).

In agreement with Busan, Pitet explained that, “I sometimes do leja-leja of digging<sup>5</sup>, though I am not strong enough to dig a large piece of land”.

Moreover, special talents like singing have helped some of the HIV/AIDS orphans to raise some financial and material support from well wishers, enabling them to address some of their challenges. Thus, the orphans are organised into choirs which are invited to entertain guests on special occasions. They have been able to do this through the help of Yaba and the other staff working at the orphanage centre. Yaba explained to me that, their objective is to provide an opportunity for the natural talents of the orphans to be nurtured so that they are able to live a constructive and meaningful life after leaving the orphanage centre. Meanwhile, for the food and medical challenges, Yenet of Liberty primary school explained that, “We work. We have a garden nearby which we dig and get our food from it”.

While for Pitet, the use of local herbs in times of illness is a practical coping strategy. “I usually boil the leaves of guava, lemon, and lomureju<sup>6</sup> and drink the fluids which come from them for treating myself. I also take some plants’ roots as medicines. I do not always attempt going to the clinic for treatment because I cannot afford to pay the medical bills”. I wanted to know from her if the local herbs really work. “Yes they do, and that is why you can see me in school like this”.

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<sup>5</sup> Digging means working the soil for farming.

<sup>6</sup> A wild plant commonly used for treating headache and fever.

From the foregoing arguments, one can deduce that, the difficulty that the HIV/AIDS orphans experience in acquiring food and medicines when they are hungry and sick do affect their school attendance and performance negatively as echoed in other studies by, Kelly, (2000), Togom, (2009) and UNESCO (2010). However, the resourcefulness of these orphans is clearly reflected in their ability to address their challenges every time they arise

Overall however, a responsible guardian/caretaker is a crucial factor in the well-being of an orphan and this impacts strongly on his/her academic or school experience. This is evidenced by taking an overview of the data collected from the HIV/AIDS orphans interviewed. As the above arguments show, most of the orphans without responsible guardians/care takers experience a number of challenges which subsequently affect their school attendance and performance. While those orphans living with responsible guardians/care takers have enough time to do their home work and study as they do not have to struggle and worry about raising their school fees or providing food and medicines in times of illness. Those without responsible guardians have to use the same time for engaging in survival activities. Busan of Liberty primary school, for instance, explained her situation as one of the lucky ones: “My maternal Aunt cares for me well and she does not discriminate between me and her real children. This makes me happy and gives me enough time to concentrate on my academic work”.

While for Yenet, his condition seems a little bit better because he is actually one of the 80 HIV/AIDS orphans being sponsored by South Sudan AIDS commission (SSAC) in Kajo-keji County. He explained that:

My school fee is paid by SSAC and when I lack some school requirements; I have a paternal uncle working with the immigration office at Jale who sometimes gives me money for buying some of the school requirements. My mother and grandmother at times help me with some money when I need it.

Nyaret, a grade four pupil of Hope primary school explained that she experiences no challenges at home because of the conducive environment provided for her by the uncles’ wife. In her own words, she explained: “At home, there is no difficulty I face. That wife of my uncle whom I live with is good. Just when I go from here, I will get that she has cooked and we eat then we shall wash the utensils”.

The foregoing narratives point to the crucial role of adults, and particularly the sensitivity of adults to the orphans’ situation. It is arguable that when adults consider the orphans situation

for example by being responsible guardians, the orphans can lead a fairly normal school life. However, in the absence of this attribute and particularly in situations where the HIV/AIDS orphans live either alone or with less caring guardians, then the orphans are subjected to facing numerous challenges which they have to battle with on day to day basis as will be elaborated upon in the discussion chapter.

### **3.1.3. Summary of part one**

The first part of the findings presented the food, material, financial and medical challenges faced by the HIV/AIDS orphans which collectively contribute to affecting their school performance. The coping strategies developed by the orphans in the face of these challenges have been presented as well. Overall, the loss of one or both parents by these orphans has made it quite difficult for them to acquire their basic needs like food, education, medical care, shelter and protection as the provision of these needs could have been the role of adults. This part of the findings only presented a summary of their food, educational and medical challenges and how they cope with them, while the effects of stigma and discrimination on their lives and the shelter and protection needs will be presented in part two of these findings.

It was found that, most of the orphans cannot afford to get their daily meal. Most of them have to spend their school days on empty stomachs. Water which is freely available in Kajo-keji County is what they can use to help them get on throughout the day, though some of them like Busan of Liberty primary school cannot concentrate in the class, particularly in the afternoon hours. As mentioned earlier, she lamented that, “in the afternoon, my eyes cannot see what the teacher writes on the chalkboard and my head turns round and round”. This according to her affects her academic performance.

Most of them, like Lomole of Hope primary school, who are not on a scholarship, find it hard to raise the money for paying their school fees. This poses a major challenge to them because, from time to time, the school administration chases them home for having not fulfilled their obligation. This frequent absenteeism from school in itself is a contributing factor to their declining school performance as a lot is missed at the school during these periods of absence. In addition, at home, they find it hard to concentrate as they have to use this time for doing some leja-leja. Moreover, even those on scholarship still face all the material challenges like their colleagues who are not on scholarship, since the scholarships offered by IGAD, through SSAC and KKLC, respectively, only cater for their school fees. Therefore, like their

colleagues who are not on scholarship, they have to work hard to meet their material needs like school uniform, shoes and paraffin as well as scholastic materials like books, pens and rulers. Moreover, in times of sickness, they have to try to look for all the local herbs known to them for treating the sickness. However, as will be seen in the discussion chapter, these daily struggles are generally even greater for the female orphans who have additional domestic and caring responsibilities.

Overall though, these orphans are very resourceful individuals. In spite of all these challenges, most of them have persisted to remain in school to date through adopting the leja-leja coping strategy where they involve themselves in doing income generating activities like selling of various items, gardening for some people and for themselves and taking local herbs in times of illness.

Elders, religious leaders, teachers and NGOs have as well aided the coping process of the orphans. For example, elders like Yaba have tried to improve their academic performance through organising extra lessons for those orphans in upper classes, in addition to buying for them text books. He also encourages them to do regular revisions of their school tasks. He together with some of the members in the orphanage centre has organised the orphans into a choir group which has helped them to get extra support. More so, some of the NGO staff have continuously encouraged the orphans to work outside their school hours in order to meet their needs. Finally, although the religious leaders and the teachers have not been able to support the orphans financially, their contribution to the well being of the orphans cannot be under estimated. Most of them, from time to time have acted as parents, advisors, guardians and counsellors to these orphans. These collective efforts have helped to keep these orphans strong in the face of multiple challenges.

### **3.2. Part 2: Stigma and discrimination (emotional) related challenges and effects on orphans schooling experiences**

#### **3.2.1. Taling and Grand Mama**

I came to learn about Grand Mama when I was interviewing Taling, one of the HIV/AIDS orphan. Taling according to our current classification of the orphans falls in the category of a total orphan because he has lost both his parents to AIDS and was handed to the uncle for care after the death of his parents. It was at the uncles' place when Taling started experiencing difficulties. According to him, his day starts at 5: 00 am in the morning when he

is expected to go and dig until 9:00 am before being released to go to school. By the time he arrives in school at 10:00 am, he cannot catch up with his class mates because two periods have already passed since classes begin at 8:00 am. Before the school day ends, Taling is expected to have come home at 12:00 pm to go and theatre the goats and herd the cattle. All these multiple tasks are done on an empty stomach since the only meal for the family is taken at 4:00 pm and is expected to keep everyone strong enough until the next day at the same time when another meal is available for every family member.

However, by the time I met Taling in Hope primary school, he had already started forgetting of all these hard conditions because luck was on his side. He had been taken in to a new home which offered him better conditions of living where he is able to go to school like any other child of his age and able to have up to three meals per day. According to his story, after the conditions at the uncles' home had become too difficult to bear, he and his sister decided to desert his uncles' home and settled at a stranger's home whom he described as a foreigner. It was at this time when Grand Mama got to learn about his suffering and rushed to his rescue.

When I finally met Grand Mama, I was curious and asked her of how Taling came to be under her care? She breathed heavily and started her version of the story:

Ohhhh my son! That was just God's plan that you should have a chance of seeing this child today. I didn't know he was going to look the way he looks today. You see, both his parents died of AIDS. Their mother died like today and after one week, their father also died. They are actually my daughters' children. He and the sister were handed to the uncle for care, but he rejected them saying they are stubborn and he has no resources to care for them. He then started to mistreat them seriously by not giving them food and not sending them to school. This male one was made to take care of animals. Shortly, their condition worsened and his sister disappeared from the uncles' home and he later followed. I hurried after being told of their situation and got them at a home of a foreigner (Grand Mama).

As our conversation progressed under the cool shade of the papaya tree which stood just two metres away from her hut, Grand Mama made a very important disclosure and it was about a child she raised but who later on turned his back on her. According to her story, she had made an investment in one of the orphans like any other responsible African by raising him with a hope that when he matures, he will support her. This hope ended up on a hard rock, as she explains.

You see Abdu, sometimes I feel I should not continue taking care of these orphans because you see, like the first child I took care of, he is now married and has refused

to help me. When I went to him for help, he told me: “Do not bring your poverty here.” I felt disappointed, embarrassed and came back home (Grand Mama).

Concerned for her feelings and the well-being of Taling, I encouraged her to forgive that young man so that she can channel her energy in caring for Taling as human beings by nature are unique. Taling might be of help to her in the future, I assured.

Moreover, Taling is not the only orphan who has undergone such difficult situations at the hands of an uncle. Not long before I met Taling and his Grand Mama, I had been discussing with Coordinator-Ayet who narrated to me a similar story of three HIV/AIDS orphans who lost both their parents to AIDS and the uncle was requested to take care of them.

Unfortunately, within a few months, these children were left homeless because the uncle decided to chase them away from his home. According to Ayet, it was not an easy task for them in trying to find a new home for these orphans, though after a long struggle, they found one.

Moreover, the experiences of Yatet of Hope primary school who lost her father to AIDS are not so different from the fore mentioned. However in her case, she lives with the sick mother and occasionally goes to the uncles’ place to request for financial and material support to meet her educational needs. According to her story, she sometimes feel that it’s better for her to struggle to support herself on her own than going to her uncle’s places because they do not have any kind words for her as they feel that they were not the ones who caused her fathers’ death. In her own words, she narrated that:

We actually have paternal and maternal uncles who could have cared for us and helped, but they are the same. They have just left us to suffer alone like this. They only care for their families and they told us that it was not they who asked my father to misbehave and contract AIDS. So, when our mother has gone for leja-leja, we are just left alone without any adult to take care of us (Yatet).

From the foregoing narratives, a number of issues are worth elaborating on. To begin with, in Africa, “a child is believed to be the root of humanity” (Bame, 2010) and more importantly, the bond between an uncle and a nephew is unbreakable. It is a common knowledge in Africa that the “bones of the nephew belongs to the uncles. What the father owns in the child is only the flesh and the blood” (Young and Ansell, 2003). Relatedly, Young and Ansell (2003) argued that:

In patrilineal societies, such as those in Lesotho and central and northern Malawi, children “belong” to their father’s brother and he takes responsibility for their care. In matrilineal societies, such as those found in southern Malawi, children “belong” to their mother’s line and orphan care is the maternal uncle’s responsibility (Young and Ansell, 2003, p.4).

Because of this strong belief, the common practice has been that if a child has been rejected by the father because of unacceptable behaviour, the father is not permitted by the culture to either mistreat or harm the child, to say the least. He is expected to send the child to the uncles’ place, “the owner of the bones”. However, the 21<sup>st</sup> century has come with many surprises to the African continent and the African people. One therefore wonders, if this emerging behaviour is due to what is now commonly referred to as “modernity” (Gyekye, (1997) or if it is because of poverty coupled with selfishness that these uncles have decided to run away from their traditionally assigned roles. An attempt to answer these questions will be made in the analysis and discussion chapter, meanwhile, in the following section; we turn our attention to more issues of stigma and discrimination which exist in various arenas in the Kajo-keji society as revealed by my participants.

### **3.2.2. The environment is not friendly to us**

As my data collection process progressed, I continued to meet more and more people to interact with and of more interest to me at this stage of the data collection were those who are HIV positive and those working with the HIV/AIDS infected and affected people. As I was discussing with Coordinator-Ayet, who is HIV positive herself, she narrated to me that the environment is not friendly for them at all and this starts right from the community where they live to even the church where they are suppose to seek refuge. I tried to follow up a point she had made:

You have talked about stigma and discrimination. Could you explain to me some of the ways in which stigma and discrimination was and is still being expressed to those who are already infected?

*Yaa, thank you very much for that question, I think I will begin from the time we started this association up to the life time, I mean up to where we are now. Even as I speak, there is still stigma and discrimination although, the level varies. By then it was really so high, but now although it is there, but at a certain level. So-o-o, Ahhh stigma and discrimination here in*

*Kajo-keji is from different areas, I think it is almost everywhere and it is of different types. People stigmatise differently, because in the hospital, there is stigma. If you go to the church where those people [HIV positive] are suppose to be counselled and helped, there is also stigma. If you go to schools, stigma is also there. And if you go to our families where all of us come from, you find stigma and discrimination. So may be, I could give you some of the examples basing on these areas I have mentioned.*

*Like for example in the hospital, we really appreciate the work the hospital is doing, because without the hospital, we would not be alive and most of us would have died. And it is because of the support the hospital is giving, for example, provision of treatment that is why some of us are alive up to today. But then you see, health workers are not the same. Some people forget their ethics, then the stigma comes, sometimes intentionally or unknowingly, when somebody has not intended. So in the hospital, the stigma we are seeing is in terms of the words which come out of these health workers. For example there was one complaint that I used to hear about a nick name that was given to them [The HIV positive]. That when they go, they [health workers] will say, “gwagwe Na Kiden”, meaning a fox is in our midst. They tell the other people that “gwagwe Na Kiden”, meaning that there is something foreign among us and therefore, you have to take care. So then when the members came to learn of this, they feel they are stigmatised. On treatment, some health workers you see reached a point of saying; why do we waste time on these people who are rotten? You see these kinds of words, meaning that we are useless. Not all health workers practice this, but a few of them do this to even the patients in the wards. So this I felt is not even fine and it discourages some of them not to adhere to their treatment.*

*And if we go to the church, we also experience the same stigma and discrimination, though with words. The words come at the time of preaching, not knowing that these people are now everywhere. They are there at where you are giving the service. And now if a word comes like, HIV is for sinners, this one straight away goes like stigmatising. Ahhh HIV is for sinners, these people who are HIV positive have been messy or have been messing around, so they deserve it, you see such words. So these are some of the stigma and discrimination we are really facing. Ahhh, in the church, that one comes when someone is preaching and that is why I say some of the stigma comes knowingly or unknowingly. It is possible that the person said that because he has an objective to achieve or maybe he was trying to pass out useful information but in a wrong way. So that is the one in the church.*



Coordinator-Ayet further explains that, much as most schools are safe havens for the HIV/AIDS orphans in Kajo-Keji, a few schools still do not have a conducive learning environment for these children due to some discriminatory practices from some of their fellow pupils. According to her, a few stubborn pupils at times give the orphans a hard time, particularly on days that their sponsors have visited them. She however generally feels that these are isolated incidences which can be handled by the teachers. She then continues with her narrative on stigma and discrimination in the community at large.

*And the biggest challenge we are now seeing is in the community. In the community, there is also stigma. Community is where we come from and is where we stay, we stay together with them. Any one time we are always together and this stigma in the community is in many ways. In the words and in isolation. These people are isolated and many other ways. In the community one of the stigmas is like one time, we were farming in Jalimo, and when we were for this activity, some other people who were even drunk came and started stigmatising these members, until these members ran away. Saying they never wanted to be near these people because of the fear that these people will infect them. S-o-o, these people were chased away, these members were chased away, but later on, we intervened. The issue is now settled and now we are going on well with our work in the farm. I think why they did that was because they were not enlightened. There was that lack of knowledge given to them. By then, they were having that fear of staying with HIV positive people, but now, we are staying with them.*

*The other stigma in the community we also had was, one time; one of the partners (NGO) went for awareness in the community. So these people were really stigmatised. One of the words from the members was that these people are given food support, which is making them healthy, and they don't deserve to be given some thing. Why are these people given food? These people should not be given food so that they die because if these people continue to be given food, they will remain happy, healthy and will continue passing the virus to other people.*

*Then again, they said, they never want these people to be near them. What they want is that these people need to be fenced up in a place somewhere because they say there is a land that is very big on Juba road. That land between Juba and Kaya is not settled by anybody. Why can't the government put a fence there so that these people are taken there? They don't want these people to be in the community. That was so stigmatising.*

*Then there was one time also from the community when we had a radio talk show. We were really not happy with the community but at the same time we were also very happy to some of the community members because they reacted so badly to that person. That person said, they never wanted these people who are HIV positive. This person was saying, there is another verse in the Bible saying that when a person is having HIV virus, that person should be destroyed. That was imagine in the public! And then, the suggestion he was giving was that better, let these people be fenced somewhere and should not remain members of the community. This is so stigmatising. But we are happy because many people reacted. Suppose he was the one who was HIV positive, would he accept to be destroyed? Will his family members accept him to be destroyed? There were many reactions to that so we are also happy.*

*Now to our families; you know, we come from different families with different levels of literacy. So to some families, life is really hard to these members. On my side I am happy because I am free from stigma. Even at family level, people have never stigmatised me. So I stand firm that up to now I am free from stigma, self stigma and even the external stigma. But one of the most serious stigmas I noticed is in the families; even we lost these members.*

*The other example was from a family where the client was denied medical treatment. The sister said she doesn't want to see this girl continue coming for treatment, then this client had to go with the decision of the sister and stopped coming for her treatment for some time and then later when she came, she was already late because she had already missed for three months. She was now to go for second line treatment which is not here in South Sudan and she had even no funds for travelling to where the treatment is. So we ended up losing this client.*

*Then the other stigma incident was when a certain client also was stigmatised by the family members- the sisters. Saying they never wanted to share the room with her and asked the mother to make sure she gets a room for this sister of theirs who is HIV positive. This girl was really healthy, but you know, stress kills. So it was sad for us to hear within a month that this client has died and we all knew, it was all about stigma that has killed this girl. So in the family, these are some of the stigma and discrimination we are facing.*

Coordinator-Ayet has raised a number of important points worth reflecting on. To begin with, she recognises the crucial role of the hospital to the continued survival of people with the

AIDS virus, but also notes that, the discriminatory attitude among some of the hospital staff has discouraged many AIDS patients from continuing with their treatment leave alone the fact that most of them get stressed and eventually become too sick (Skinner and Mfecane, 2004, Link and Phelan, 2006; Asiedu, 2007 and Christian Aid, 2008). More so, she persuasively puts it that, much as the religious leaders sometimes sound stigmatising in the church, and particularly during preaching, most of them do that unknowingly.

She also carefully notes how stigma in the family seems to have led to the death of some of their members, an argument which has been advanced in other studies, more empathically by Asiedu, (2007). Moreover, at the community level, she explains that some community members favour isolation of the HIV positive members of the society from the rest of the community members (Christian Aid, 2008), though she also notes that this radical position has been rejected by most of the community members. She further acknowledges that though a few stubborn pupils can be a threat to some of their colleagues who are both infected and affected by AIDS, the teachers on the other hand can be of help in shaping their behaviour (Nsubuga and Jacob, 2006). All these issues raised will be elaborated upon in the discussion chapter.

Project officer-Kudot also added his voice to that of Coordinator-Ayet and explained that;

Yes indeed, stigma and discrimination are some of the challenges we are confronting. What actually create fear to go for testing are the consequences of stigma and discrimination. Usually people who have tested positive report of feeling inferior, unwanted and feeling like being out of their skin. The club members (KKLC) report being nick named. For instance, “this is a moving grave” or saying that in our language “na mone a tekeyek”<sup>7</sup> (Project officer-Kudot).

Relatedly, Yaba argued that, in the school; much as the pupils are quite innocent and less harmful to the HIV/AIDS infected and affected pupils, the teachers on the other hand are not and he narrated that:

We have not received a case of discrimination from their fellow pupils but instead from the teachers. For instance on Tuesday, some children came to me and reported cases of two pupils who uprooted certain woman’s groundnuts. Of the two pupils, one of them is an orphan and the other one is not. The most stressful situation for the orphans came the following morning when the teacher was addressing the pupils during assembly. Instead of pointing the mistake to the individual pupils, the teacher

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<sup>7</sup> A Tekeyek is a musical instrument, usually played by religious women during funerals. The expression “na mone a tekeyek” means the sick person now smells that musical instrument.

made a general statement that the woman's ground nuts were stolen by the orphans. This pained the hearts of the other orphans who did not get involved in the act; feeling that they have been discriminated against. He generalised that all the orphans are stubborn and added that if there was another school nearby, they would have asked all the orphans to transfer to those schools (Yaba).

These narratives give a broad picture of the attitude of the people of Kajo-keji County; South Sudan toward the HIV infected and affected persons. As coordinator-Ayet has commented, this could be because of general ignorance among the population on what HIV is, how it is acquired/ spread, and how it can be prevented. It also presents the population's general lack of knowledge on how to care for the infected, suggesting a huge task for the government and all development agencies working in the field of HIV /AIDS to raise their level of awareness among the population so that some of the deaths due to stigma and discrimination can be prevented. I was sceptical from the beginning about taking every detail of the above narratives at face value. In an attempt to cross-check this information, I decided to interview a number of stakeholders whose institutions have been mentioned by Coordinator-Ayet and Yaba as responsible for stigma and discrimination and interestingly, they confirmed to me that such practices do exist among their members but promised that they will put an end to them because there are some measures they have already developed for curbing them.

The church leaders for example, explained that they have already started conducting workshops for all their religious leaders (pastors and lay-readers) on the importance of appropriate language use while preaching and on their responsibility as religious leaders to emulate Jesus' example by working as Sheperds. They are advised to give more love and pay more attention to their members who are HIV positive. However, they also reported that this practice has attracted a lot of criticisms from some of the church members who asked: "Why do you give more love and pay more attention to people who are sinners? Are you not also encouraging us to become promiscuous?"

While in the health sector, the officers' in-charge in both Kajo-keji civil hospital (KKCH) and ARC; the two institutions responsible for HIV counselling and testing explained that out of a total number of 462 (cumulative data from 2005 to 2010) HIV positive persons in the County, there are 231 of them on treatment. 52 have already developed AIDS and are on ARV treatment and are adhering to it while the other 179 are on prophylaxis<sup>8</sup>. These are

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<sup>8</sup> The word prophylaxis is a medical term which means 'preventive medicine or preventive care' against a disease.

people who are said to be in HIV stage one and two who don't have any medical condition of any kind and these are people whose CD4 count is above 350.

However, both officers complained that cases of defaulting<sup>9</sup> are very common among those who have tested positive;

We have a very big number of people who have tested positive but they default. They can come like today, get tested, informed of the results of the testing and may decide not to come back. That is our problem here in kajo-keji. Even though how much we teach them, some do not follow. They go like that and stay until a day when they are transported to the hospital by someone again (Melesuk and Gordon).

Moreover, defaulting leads to development of resistance by the body to the use of same AIDS drugs resulting in weakening of the body's immunity, making it prone to opportunistic infections. According to Melesuk, this has led to the death of many HIV/AIDS infected persons and by October 2010, 291 children in Kajo-keji County alone have been left orphans.

### **3.2.3. "Safe havens"**

There is the other side of the story. Most of the teachers and the learners in the schools I conducted the study in argue that schools are safe havens for both the HIV infected and affected children where stigma and discrimination does not exist. The school administrators explained that they have created an inclusive culture and policies in their institutions which create a conducive learning environment for every pupil.

Deputy Head teacher-Malual of Liberty primary school argued his point by explaining that; "You know that HIV/AIDS is like any other disease these days, and it is not for specific people but it is for all". Teacher-Lokutuk of Hope primary school seems to agree with Deputy Head teacher-Malual and explained that;

We have not experienced any cases of stigma and discrimination here in the school. These children always play together during break and if it is time, they come in and also in the class, they also work together. So there is no problem. Cases of discrimination are due to lack of education. HIV/AIDS is not like tuberculosis that you can contract through the air. So if the children are well educated about how AIDS is spread, then there will be no cases of stigma and discrimination (Teacher-Lokutuk).

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<sup>9</sup> An act of refusing to continue with ARV treatment by HIV positive persons.

Head teacher-Golyan also dismissed existence of stigma and discrimination in his school. This was how he argued it “Stigma here! Within the children? Haaa I have not seen. May be in the community where we don’t know but within here, No”.

I tend to agree with the above arguments. As the above narratives have pointed it out, Head teacher-Golyan’s arguments about existence of stigma and discrimination in the communities where the HIV/AIDS orphans come from could be something to go with. However, in the schools, it is likely that the existence of stigma and discrimination is not noticeable. This has been my experience during the field work as it proved almost impossible for me to distinguish between the HIV/AIDS orphans and the rest of the pupils both during social and class hours throughout the two months period of my studies.

Nyaret, a pupil in Hope primary school is one of the HIV/AIDS orphans I had interviewed to find out whether stigma and discrimination do exist in their school. When asked whether she thinks the other pupils are aware that the pupils in the school whose school fees are paid by the loving club (SSAC) lost their parents to AIDS, she replied that. “I don’t know also, but if not they didn’t know because they don’t say some bad things to us”, When I interviewed the rest of the HIV/AIDS orphans in the two schools on the same issue, they all affirmed Nyarets’ position. For example, Lomole explained that “my class mates are very good. We are good friends together. We play and share everything we have. This makes me feel very happy”. Considering the level of consistency right from the Head teachers’, teachers’ and the HIV/AIDS orphans’ statements in regards to the existence of stigma and discrimination in the schools, it may be safe to conclude that the schools where these orphans learn in are indeed ‘safe havens’.

As the Head teachers have argued, this could be attributed to a number of factors. For example, the strict school rules and regulations and the practice of praying regularly developed by the two institutions. Throughout my period of the field work, I noticed that prayers characterised by preaching every morning was compulsory for every pupil and during the preaching, the pupils are urged to love one another and treat each other as brothers and sisters. This practice to a greater extent might have contributed in changing the attitude of those pupils intending to discriminate against their colleagues who have been orphaned by AIDS.

### **3.2.4. Is it AIDS or stigma and discrimination?**

There seems to exist various schools of thought explaining why HIV positive persons die. Some, for example, the medical personnel attribute the death to opportunistic infections which tend to attack the body once its immune system is already being weakened by the AIDS virus, while others are of the view that, stigma and discrimination are responsible for the death of thousands of HIV positive persons (Skinner and Mfecane (2004); Link and Phelan (2006); and Asiedu (2007). This latter view seems to be the school of thought to which most of the participants in this study who are HIV positive themselves belong to. As will be evidenced by their narratives below, most of them argue that with an environment free from stigma and discrimination, they can live with the virus for a long time. Project officer-Deborah, a key informant in this study who has been living with the virus for a long time had this to say:

I am living positively and a widow. I have lived with the disease for over 20 years and I am prepared to live with it for the next 100 years. This is because I enjoy a lot of love, care and support from the people around me. Remember; I told you that two of our members died within a short period with the disease because of being stigmatised and discriminated against. I had told you of the one who died only after three years because the family members refused to eat, sleep and discuss with her and the other one who took only two years because the sisters refused to allow her go for treatment and could not give her attention in every respect and you see, both of them contracted the disease after me, but both have died before me. Therefore, if all the HIV positive persons are to receive similar treatment from the people around them like me, they would have lived for a long time and as of now, we would not have been hearing of HIV/AIDS orphans because these parents would have been still living with their children (project officer-Deborah).

Project officer-Deborah seems to be suggesting that, with an environment characterised by love, care support and meaningful company, HIV positive persons can live for a long time. Moreover, another participant who is also HIV positive testified to me that:

...I think I have lived for lo-oong with the virus now? I think the time I realised that I was HIV positive was in 2006. That is how I realised that I am living with something foreign in my body. So from 2006 up to now is like 4-5 years. But it is possible that I have lived with the virus for a longer period than this because I do not know for how long it had been with me before I tested in 2006. I am living in a positive life and it is my belief and hope that I will still live for many -many years because I still have the young ones and I still have the youngest as I speak, the one I must call the youngest. He is one year and nine months. I conceived with him when I knew that I was already HIV positive and then I enrolled in to the PMTCT and up to now, he is HIV negative. It is my hope that I will live and see them grow, and I must educate them. So I must live for some more years, and as far as my health is concerned, my health is okay and my CD4 cell count is okay in my body because of recent, I tested and I was like still

having 1300 CD4 cells in my body which is oka-aye and my partner is also still strong. So unlike the others, I enjoy a lot of love and care around me (Coordinator-Ayet).

Both narratives downplay the fact that AIDS kills and yet, this doesn't seem to appear a wild claim because they are able to give practical examples of people who contracted AIDS after them and died before them. However, these claims will be investigated further in the analysis and discussion chapter.

### **3.2.5. Summary of part two**

The second part of the findings presented the scope of the emotional challenges faced by the HIV/AIDS orphans which stem from the unfriendly environment they live in characterized by stigma and discrimination at all levels of the society. In addition to losing their parents, these orphans are faced by yet another challenge of being rejected by their closest relatives like uncles who are suppose to console them by providing for them a home to live in. Many other orphans like Taling and his sister are examples of such situations. Some of the lucky ones have been provided a home to live in by their grandmothers or other relatives while some have remained homeless; hence, they have to struggle on their own.

Moreover, stigma and discrimination in Kajo-keji County is experienced by both the HIV/AIDS infected and affected members at all levels of the society. As coordinator-Ayet had argued, this practice starts right from the family to the hospital, church and covering the whole community. The effect of this on the HIV positive persons is frequent defaulting coupled by rising levels of stress among the infected members. As (Asiedu 2007; Link and Phelan 2006 & Skinner and Mfecane 2004) have argued, high levels of stress complicates the treatment process, eventually leading to the death of these members. As death robs these members of the society away, more children are left as orphans.

On a more negative note, stress seems to be occupying a central position in the life of the orphans. Other than the stress they experience from losing their parents, they have to battle with another type of stress on a daily basis and almost throughout their lives. This stress originates from the state of nothingness surrounding them. Lack of money for financing their education stresses them every day. In addition, the absence of materials like school uniform, shoes and scholastic materials like books, pens and rulers is another source of stress. Though Ebersohn and Eloff, (2002) argues that low level stress motivates the orphans to work harder



in order to cope with the challenges, stress at its extremes is a source of some health problems to the orphans (Link and Phelan, 2006).

In conclusion, it is important to note that, despite the unfriendly environment characterised by stigma and discrimination surrounding the orphans at the community level, some of the schools these orphans go to have become safe havens which are free from prejudice. This argument has been confirmed by both the pupils [orphans] and the teachers in the schools which were part of the study.

### **3.3. Summing up part one & two: Food, Financial, Material, and Emotional challenges and coping strategies**

The two parts of the findings collectively presented the educational related challenges faced by the HIV/AIDS orphans and the coping strategies they have developed. The challenges include, amongst others food, financial, material and emotional challenges. The main coping strategy developed by the orphans is the leja-leja coping strategy. The leja-leja coping strategy is reported to have been strengthened by the aid of stakeholders like governmental and nongovernmental organisations, community based organisations and faith based organisations in addition to the crucial role played by religious leaders and teachers.

Furthermore, the persistent prevalence of stigma and discrimination in the Kajo-keji society unfortunately has contributed to early deaths among HIV/AIDS positive members of the society, leaving many children as orphans. As Coordinator-Ayet, Project Officer-Deborah, Asiedu (2007) and others have argued, stigma and discrimination leads to rising level of stress which tend to complicate the treatment process, resulting in death among AIDS patients. On a positive note however, most schools in Kajo-keji County have been reported to be relatively free of stigma and discrimination, and it is only in these institutions that the orphans find a conducive environment for learning.

## **Chapter Four: Discussion and Analysis**

### **4.0. Introduction**

The HIV/AIDS pandemic has evoked a wide range of reactions from individuals, communities, and even nations, from sympathy and caring to silence, denial, fear, anger, and even violence. Stigma is an important factor in the type and magnitude of the reactions to this epidemic (Malcolm et al. 1998 in Brown et al., 2001). Moreover, the victims of these reactions have to try to cope with these situations on daily basis. This chapter presents the discussion and analysis of the findings of the study which attempted to investigate the education-related challenges faced by HIV/AIDS orphans and the coping strategies they have developed both on their own and with the help of stakeholders. Where necessary, I will try to link some of the issues which have emerged in the various themes to some relevant concepts or theories.

Some of these concepts include stigma and discrimination (Goffman, 1963; see also Asiedu, 2007; Genberg et al, 2009; Deacon, Stephney & Prosalendis, 2005; Ogden & Nyblade, 2005; Petney, 2010); socialisation (Berger and Luckmann, 1966; Giddens, 2006), coping (Germann, 2005; Ntozi, 1997; Togom, 2009) and tradition and modernity (Bredlid, 2002; Gyekye, 1997) .The discussion and analysis will be done under two broad themes of stigmatisation and coping strategies. The first part of the discussion will show how stigmatisation is a major factor impeding the HIV/AIDS orphan schooling experiences, while the latter will examine the strategies the HIV/AIDS orphans have developed for coping with these challenges.

### **4.1. Part one: Stigmatisation and discrimination**

#### **4.1.1. Definitions of stigma and discrimination**

This section is intended to provide the reader with a general understanding of stigma and discrimination in various arenas right from the family to church, hospitals and the general community. Both the perspectives of my research participants and that of other researchers who have conducted related studies will be presented. However, I want to start by defining some of the key words which have formed the basis of the discussion in the first part of this chapter. These are stigma and discrimination.

Stigma has been defined as an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society (Goffman, 1963; see also Aggleton, Wood & Malcolm, 2005; Deacon, Stephney & Prosalendis, 2005). Under

Goffman's definition, stigmatization is the societal labelling of an individual or group as different and the difference seen in the other person or group in this case is used as a basis for discrediting him or her. HIV-related stigmatization, then, is a process by which people living with HIV are labelled and discredited. This practice does not only affect those directly infected by HIV, but even those affected by AIDS by association, such as orphans (Aggleton, Wood & Malcolm, 2005). As argued elsewhere by Link and Phelan, (2006), discrediting leads to the development of stress which tends to complicate treatment processes, eventually leading to the death of the infected person.

Others have defined stigma as social processes that are linked to societal power structures (Link 2001; Parker 2001). This implies that the process of stigmatisation involves two parties, the powerful (stigmatiser) and the powerless (the stigmatised). These power structures facilitate the creation of "us" and "them" images. The "us" refers to those who are HIV negative and therefore defined as normal and consequently powerful relative to the "them" who are HIV positive and marginalised due to the negative perceptions associated with HIV/AIDS.

Several authors divide stigma into felt or perceived stigma and enacted stigma (Malcolm et al. 1998; Scrambler 1998; Scrambler and Hopkins 1986). Felt stigma refers to an individual's real or imagined fear of societal attitudes and potential discrimination arising from a particular undesirable attribute or disease (such as HIV), or association with a particular group. This fear tends to force the individual to deny his/her risk of HIV, refuse to use condoms, or refuse to disclose HIV status in order to avoid the possible negative reactions of family, friends, and community. This argument is consistent with some of the findings of this study. For example, some of my participants such as project officer-Kudot, coordinator-Ayet and medical officer-Melesuk argued that most HIV positive persons in Kajo-keji fear disclosing their status because of possible negative reactions from the community and some of the people close to them. Similarly, the secondary data reviewed revealed a similar phenomenon in some parts of the Sudan, particularly in Khartoum (Christian Aid, 2008). On the other hand, enacted stigma is action based on stigma and is, usually carried out by the powerful or those who are HIV negative. For example, the disclosure of an individual's HIV-positive status could lead to loss of a job or health benefits, (Brown et al., 2001). Christian Aid (2008) similarly presented a similar argument from its study conducted in Khartoum,

Sudan. It explained that most HIV positive persons in the Sudan who have disclosed their status cannot succeed in finding a job, even though they have the necessary qualifications.

“When stigma is acted upon, the result is discrimination” (Aggleton, et al 2005, p.9).

Discrimination in relation to HIV/AIDS may be referred to as “what people do to unfairly disadvantage people living with HIV/AIDS” (Deacon, Stephney & Prosalendis, 2005: ix).

Aggleton et al (2005) further argued that, discrimination consist of actions or omissions that are derived from stigma and directed towards those individuals who are stigmatized.

Therefore, stigma and discrimination are interrelated, reinforcing and legitimizing each other.

Stigma lies at the root of discriminatory actions, leading people to engage in actions or omissions that harm or deny services or entitlements to others. A typical example of this is the actions of some of the medical staff in Kajo-keji County against the HIV positive members. They deliberately chose to call these members “foxes” and “rotten” causing harm on them seriously (coordinator-Ayet). Aggleton et al, (2005), contend that, stigmatizing and discriminatory actions violate the fundamental human right to freedom from discrimination.

In addition to being a violation of human rights in itself, discrimination directed at people living with HIV or those believed to be HIV-infected, leads to the violation of other human rights , such as the right to health, dignity, privacy and freedom from inhuman, degrading treatment (Aggleton et al, 2005). According to UNAIDS (2000), discrimination refers to any form of arbitrary distinction, exclusion, or restriction affecting a person, usually but not only by virtue of an inherent personal characteristics or perceived belonging to a particular group. In the case of HIV/AIDS, a person’s confirmed or suspected HIV positive status, irrespective of whether or not there is any justification. The following section starts the discussion by providing a general picture of stigmatization and discrimination practices within various arenas of the society.

#### **4.1.2. Stigmatisation in society in general**

I will be discussing the concept of stigma in relation to my research questions of which the first asks about the education-related challenges the HIV/AIDS orphans face. As presented in the findings chapter, the HIV/AIDS orphans face numerous challenges, of which the stigma and discrimination reflected in denying some of the HIV/AIDS orphans shelter is just one of them. As it has been pointed out by participants like Grand Mama and coordinator-Ayet in the findings chapter, several of the HIV/AIDS orphans have been left homeless by their closest relatives. This act is more instrumental in causing some of the challenges they are

going through, like inability to pay school fees and acquisition of scholastic materials, lack of food, clothing and parental care and love.

In reference to the foregoing, it is worth asking how the above scenario impacts on their school attendance and performance. To begin with, the impact of these challenges on their school attendance and performance is a cause for concern. As pointed out by Coordinator-Ayet, many of them who had joined school before have had their regular school attendance disrupted and in some of the worst case scenarios, it has resulted in them dropping out of school.

Not only is their school attendance and performance affected, but their socialisation process as well. As these orphans are uprooted from their uncles' homes, they lose touch with their primary agents of socialisation such as the family (Berger & Luckmann, 1966; Giddens, 2006). Moreover, as pointed out earlier, absence of a home for a child to live in means losing the opportunity to go to school and thus access important secondary agents of socialisation. These socialisation processes are very important for the normal growth of the child into the societal life.

Socialisation is the process whereby the helpless infant gradually becomes a self-aware, knowledgeable person, skilled in the ways of the culture into which he or she was born (Giddens, 2006, p.163). The above definition seems to suggest that an infant needs someone or in this case a significant other to make him or her aware, knowledgeable and skilled in the ways of the culture into which he or she is born. However, what would happen to a child in the absence of the significant others? One possibility is that a child will fail to get socialised into the society, meaning that, this child in later years will not have feelings of belonging to the community he or she is born in to since that orientation to aid his or her integration process in to the society was not done. As Berger and Luckmann, (1966) argue “an individual is not born a member of society, but born with a predisposition towards sociality, and becomes a member of a society as he or she is being socialised in to it” (Berger and Luckmann, 1966, p. 149).

In relation to the HIV/AIDS orphans, this argument seems to suggest that these orphans will fail to be socialised into their society unless a home is found for them where the guidance of

significant others like adult caretakers/guardians, peers and friends are available for aiding their socialisation process into the society. Though some of the orphans in this study have been able to get good care takers like Taling who now lives with Grand Mama, this is not the case with the rest of them. The others, like the ones being reported by coordinator Ayet, are in the process of being settled. However, how conducive and permanent this settlement will be, still remains a challenge.

Moreover, children need adults and other primary socialisation agents to attend to their emotional needs. Like any other person, the HIV/AIDS orphans need love, care and protection in the course of their growth. They need to share their love with someone else and also need to be consoled when in pain. This pain could be both psychological, for example when he or she is stigmatised and discriminated against, and physical, when abused through beating. In the absence of someone to provide such care, some children can become so stressed that they eventually begin developing health complications with negative consequences to their bodies (Aggleton, 2000; Asiedu, 2007; Genberg, 2009; Ogden & Nyblade, 2005; Petney, 2010). A practical example of this scenario in this study is the three orphans who have been abandoned by their uncle as reported by coordinator-Ayet in the findings chapter. According to her, by the time she came to these orphans' rescue, they had started suffering from bad headaches which were not responding to treatment and sleepless nights. On a positive note however, their health condition improved after finding for them a home (Coordinator-Ayet).

These negative childhood experiences are not isolated incidences typical to only South Sudanese HIV/AIDS orphans. These findings are consistent with what other researchers have found out in various parts of the world. For example, Petney in his study conducted in India titled: "Experiences with HIV/AIDS and the HIV/AIDS-related stigma among infected and affected children in India" reported that most HIV positive children in India who unfortunately have lost both their parents to AIDS got themselves rejected by closest relatives like uncles and grandparents because of the fear that these infected children might infect the other HIV negative family members (Petney, 2010). Similarly, Germann (2005), in his exploratory study on orphans in child-headed households in Zimbabwe explained that poverty is a major contributor to discrimination as many families are unable to meet their basic needs including education for their own children. Therefore, denying shelter to the

HIV/AIDS orphans is seen as a better option of avoiding the extra burden of caring for many children whose presence may affect the family more.

However, some researchers attribute these discriminatory practices to ignorance or lack of education about HIV/AIDS and how it is spread. For example, Siegel, Lune, and Meyer, (1998) maintained that HIV positive men in a study she conducted attributed discriminatory tendencies by HIV negative individuals towards the HIV infected persons to their ignorance about the disease. This argument seems to agree with the findings of this study. For example, Teacher-Lokutuk in Hope primary school argued that; “stigma and discrimination in schools is due to ignorance of the population on how HIV is spread”. He argued that HIV/AIDS is not like tuberculosis which can be transmitted through the air and therefore the presence of HIV positive children in the school is not a threat to the well- being of the other HIV negative children. To him, proper education on what HIV/AIDS is and how it is spread is a key to eliminating stigma and discrimination in all educational institutions and the community at large.

In reference to the foregoing, I found the former prime minister of Tanzania’s arguments on the same issue worth mentioning. He argued that:

‘If we are to address stigma, we must first understand it. We should focus our attention on understanding what causes us as a society to react in this way to people living with HIV/AIDS — people who are suffering enough, either physically or mentally to be challenged yet again by the judgment of others, by the very people who yesterday were their neighbours and who should be reaching out to them today. Only when we understand the cause can we hope to help our fellow men and women react in a more compassionate and human way.’ (The Prime Minister of Tanzania, Hon. F T Sumaye in the Regional Consultation Report, 2001, in Skinner and Mfecane, 2004, p.158)).

This argument strongly agrees with the findings of this study. As Skinner and Mfecane (2004) have put it, if we have to fight stigma, then we need to understand the cause. My participants attribute stigma to ignorance and therefore called for massive awareness creation programmes to enable people get an understanding of how AIDS is spread and how it is not, and the rights and wrongs associated with people who are HIV positive. Their arguments were that while some work has been done in this area, still much more needs to be done by both the government and the NGOs in South Sudan. I do agree with these arguments because my understanding of the situation in regards to people’s knowledge on HIV is that less than

half of the population of South Sudan is aware of what HIV is, how it is transmitted and how it can be prevented. The low literacy rate in the country partly has contributed to this, though other factors like the low level of sensitization on HIV/AIDS cannot be ignored. This has been confirmed by the UNGASS progress report published in 2010 which argues that:

Knowledge of HIV still remained very poor in South Sudan, as the level of education was low, many people still lived in denial of the risk, infrastructure was in poor state and there was little behavioural change and communication work, especially at the community level (UNGASS, 2010, p.29).

However, I argue that this situation could change considering the governments' changing attitude towards fighting and possibly eradicating the disease in collaboration with its partners.

To summarise this general section, I want to elaborate briefly on two important concepts which have emerged from the data on stigma and discrimination. These are directly felt stigma and indirectly felt stigma by the HIV/AIDS orphans. In reference to this study, directly felt stigma refers to negative experiences of stigma and discrimination directed against the HIV/AIDS orphans at homes and schools by closest relatives, peers and friends. On the other hand, indirectly felt stigma is that kind of stigma directed against the HIV positive parents of these children which result in rapid deterioration in their health conditions leading to early death from AIDS. This type of stigma is referred to as indirectly-felt stigma because in as much as it is not directed against the HIV/AIDS orphans, it still affects them as the death of their parents is what has resulted in their becoming either single or double orphans. It is upon this latter type, the indirectly felt stigma that the following section will focus, looking especially at stigma in the family, churches, hospitals and the community at large.

#### **4.1.3. Stigmatisation in the family**

According to some of the participants of this study, stigma in the family is one of the major causes of death among HIV positive persons and it is the reason for having HIV/AIDS orphans today. One of my participants in particular, who is HIV positive herself, argued that without stigma, HIV positive persons can live for a very long time. She provided two contrasting examples to support her argument. She used herself in the first example and explained that, "I am HIV positive and a widow. I have lived with the disease for over 20 years and I am still prepared to live with it for the next 100 years. This is because, I enjoy a



lot of love, care and support from the people around me” (Project officer-Deborah). She is implying that HIV positive persons need love, care and support and more importantly, acceptance by every family member that they are still useful to the family. This environment she lives in with reduced stigma and discrimination is what, according to her, has contributed to her good health despite the virus.

The next example she gave to contrast hers is of two members of the Southern Sudan network of people living with HIV (SSNeP+). According to her, these members contracted the virus after her. However, because of being stigmatised and discriminated against at their homes by their own family members, they died within a short period of two and three years respectively. In her own words, she argued that:

Remember, I told you that two of our members died within a short period with the disease because of being stigmatised and discriminated against. One died only after three years because the family members refused to eat, sleep and discuss with her and the other one took only two years because the sisters refused her to go for treatment and could not give her attention in every respect (project officer-Deborah).

In her concluding remarks, she asserted that, “if all the HIV positive persons are to receive caring attention from the people around them, they would have lived for a long time with the virus and as of now, we would not have been hearing of HIV/AIDS orphans because these parents would have been still living with their children”.

I found Project officer-Deborah’s comments meaningful and I seem to concur with her claim which has some strong backing from available literature on the topic. Studies conducted by (Asiedu, 2007; Link and Phelan, 2006; Skinner and Mfecane, 2005) seem to agree with Project officer-Deborah’s claims. For example, Skinner and Mfecane (2005), in their studies on stigma and discrimination argued that, stigma and discrimination play significant roles in the development and maintenance of the HIV epidemic. They emphasised that; “it is well documented that people living with HIV and AIDS experience stigma and discrimination on an ongoing basis” (p.157). When stigma is experienced at the family level from people who are considered as closest and most trusted, it must be expected that trust in others and especially in care-givers is destroyed. The result is that the constant stigmatisation and discrimination tends to disrupt the functioning of communities as well as complicating prevention and treatment of HIV (Skinner and Mfecane (2005). They further clarified that, discrimination has significant impacts on diagnosis and treatment (p.161). For the individual,

it can delay diagnosis and therefore also delay entry into treatment and adoption of a healthy lifestyle. Therefore, there is no motivation to be tested, as the person sees no benefit when the diagnosis of HIV is seen as equivalent to death, and yet, they are likely to experience more discrimination, they concluded. This argument implies that there is very strong relationship between earlier death of HIV positive persons and stigma and discrimination, hence justifying Project officer-Deborah's argument.

Another study by Link and Phelan (2006) provided an informed argument which links stigma to stress and eventually death. They argued that, "the extent to which a stigmatised person is denied the good things in life and suffers more of the bad things has been posited as a source of chronic stress, with consequent negative effects on mental and physical health" (p.528). They emphasised that; the stress associated with stigma can be particularly difficult for those with disease-associated stigma. Not only are they at risk to develop other stress-related illnesses, but the clinical course of the stigmatised illness itself may be worsened and other outcomes affected, such as the ability to work or lead a normal social life. Indeed, the fear of being labelled with the disease may cause individuals to delay or avoid seeking treatment altogether, while those already labelled may decide to distance themselves from the label, forgoing treatment or becoming noncompliant. As Link and Phelan (2006) argue: "When either of these processes operates, people suffer the consequences—tragically, including death" (Link and Phelan, 2006:529).

This argument strongly backs the claim by my research participants that the common cause of death among HIV positive persons is not the AIDS itself but the stigma associated with it. Considering the strength of this argument, then it is arguable that AIDS related deaths can be delayed if not avoided by developing proactive policies gearing towards elimination of discriminatory and stigmatising attitudes among people in the community. When this is done, then it is not unlikely that we will begin witnessing a drop in the number of children becoming orphans as a result of losing their parents to AIDS.

Asiedu (2007) in his study of stigma and discrimination seem to concur with the foregoing arguments. Quoting from several sources (Deacon & Myers-Walls, n.d; Ogden & Nyblade, 2005; Smart, 2005), he claims that, PLHA suffer emotionally, physically, economically and socially. They lose their jobs/livelihood, access to service, status and sense of self and

therefore stigmatization and discrimination become an additional stress. In addition, physical isolation and violence are painful and hurtful to PLHA, because it is something that they experience physically. PLHA see people isolating themselves from them and distancing themselves from them. “This distancing creates a gap between PLHA and their friends and society and they are not given the respect and authority due them. This eventually leads to stress which is a cause of death to many” (Asiedu, 2007: 14). It seems reasonable to conclude that such isolation and stress are felt more intensely when it comes from the family.

To conclude, the HIV virus is generally seen as a threat to the lives of the infected because of its ability to weaken the body's immune system by destroying the white blood cells hence giving a chance for opportunistic infections to attack and finally weaken the body (Sowadsky, 1999 in Asiedu 2007). However, some of the HIV positive persons do not see this argument as the major cause of death among them. Their reservation is based on the fact that many HIV positive persons who are not subjected to stigma and discrimination can live with the virus for over 20 years and still show no signs of infection in their bodies as is the case with Project officer-Deborah who explains that her continued good health is due to the love, care and support she gets from her family. This implies that, these findings can be used as a basis for starting a very important war against stigma and discrimination so that unnecessary deaths which come as a result of them are minimised. Though it can also be argued that the above scenarios occur because of the different ways people respond to the virus. Some tend to show strong resistance power to it resulting to prolonged life while others do not simply withstand it. The next section discusses stigma and discrimination in the hospitals and health centres in general.

#### **4.1.4. Stigmatisation in the Hospitals and health centres**

The Hospitals and Health centres are some of the arenas where stigma and discrimination against the HIV positive members of the society is manifested explicitly. The consequence of this kind of stigma is frequent defaulting by the HIV positive persons in their routine treatment and the result of it is again early death which in turn gives rise to large number of children being left orphans. The findings of this study show that there is a very high level of stigma and discrimination against those members of the society with sero-positive status in Kajo-keji County, South Sudan. This is manifested through labels given to them or through nick-naming practices and intolerable utterances. For example, Coordinator Ayet explained that, the hospital staff have nick-named the HIV positive persons as foxes because they are

equated to killers. Across many South Sudanese societies, a fox has a very bad reputation because of its habit of killing chickens in the homesteads. According to Coordinator Ayet, as soon as the medical staff see an HIV positive person in the hospital, he or she will immediately alert the other patients by saying that “gwagwe na- Kiden” meaning a fox is in our midst, signalling that everybody should be careful because of the visible threat. According to her, this practice resulted to massive defaulting by many HIV positive patients who had earlier on enrolled in the ART programme.

This statement was confirmed by the Head of the ART department in the hospital who explained that many people who have tested HIV positive would not like to come back again to continue with the treatment on their own. “They come, test positive and are next seen when they are lifted to the hospital by some family members” (Medical officer-Melesuk). According to Melesuk, one of the participants in my study, some utterances from the hospital staff like “why do we waste our time in treating people who are rotten” worsened the situation leading to a drastic reduction in the number of people reporting to the hospital for testing and treatment.

However, what are the sources of stigma? In the hospital and Health context, Brown et al (2001) explained that there are three sources of stigma. These include; fear of illness, fear of contagion, and fear of death. According to him, fear of illness and fear of contagion is a common reaction among health workers, co-workers, and caregivers, as well as the general population (Brown et al., 2001). The fear of contagion, illness and death could be some of the reasons why the hospital staff and some of the care givers decided to distance themselves from the HIV positive members at a time when their services are badly needed. As explained by coordinator-Ayet, this practice ultimately may have increased the stress levels in these patients leading to frequent defaulting and subsequently death. Unfortunately, the consequence of this is the increase in the number of children left as orphans.

Defaulting due to discrimination according to Skinner and Mfecane (2004, p.160), “make the epidemic invisible”. They argued that:

A prime impact of discrimination is that it pushes the epidemic underground, forcing people who have contracted HIV, and anything else associated with the disease, into hiding. An acknowledgement of HIV becomes difficult if not impossible. Likewise any association with the disease or people with HIV can be a basis for that person

being excluded from their community, so the person is denied. The disease itself then remains hidden so its perceived threat is reduced. It also makes the disease someone else's problem (Skinner and Mfecane, 2004, pp.160-1)

The stigmatising beliefs then facilitate the use by individuals and communities of denial and distancing as defensive processes against the epidemic (Skinner, 2001 in Skinner and Mfecane, 2004; Christian Aid, 2008).

An important point to consider in the foregoing argument is that discrimination encourages the disease to remain hidden in the communities, meaning that many infected persons end up dying of AIDS at their homes without the actual cause of death being recognised; making it very difficult for appropriate prevention and treatment programmes to be developed. In some societies, such mysterious deaths from unknown diseases are attributed to witchcraft practices (Schnoebelen, 2009). Although many studies have not yet been conducted on this subject to substantiate the claim, except the few like that of Schnoebelen (2009), it is likely that the rampant stigma and discrimination practices against the HIV positive persons in South Sudan could be one of the reasons explaining the seemingly low HIV prevalence rate in the country of 3.1% (UNGASS, 2010). However, the truth could be alarming if exposed since many with the virus could still be in hiding.

Elsewhere, (Aggleton, 2000; Asiedu, 2007 and Mawar et al, 2005) it is contended that there are a wide range of feelings exhibited by clinicians about HIV positive persons who often made moral and non clinical attributions about individuals' past "misbehaviour, "and "misconduct". Moreover, a few health service providers reported fear of touching HIV/AIDS patients. In addition, they argued that hospital practices, such as a separate AIDS wards, HIV diagnoses on open charts, and the conspicuous use of biohazard labels serve to discriminate HIV/AIDS patients. Aggleton et al (2005) further argued that researchers in India found that people living with HIV and their care givers reported receiving differential and discriminatory treatment from health-care workers. This was evidenced by practices such as accommodating HIV-positive persons in isolated wards, early discharge from hospitals, delays in surgery and serious breaches in confidentiality.

Arguably, these are some of the practices discouraging community members from attending HIV/AIDS counselling and testing services as the result of the test might mean obtaining a

different label on one's self with negative connotation by the very people who are suppose to console one. Moreover, this practice may discourage those who have tested positive from coming to the hospital for routine check-ups and treatment and the few who may continue with the treatment do it with excessive levels of stress. All these contribute to shortening of the lives of those who are HIV positive and the result of this is nothing other than leaving of many innocent children as orphans.

However, other researchers such as Brown et al (2001) assert that, the public must exercise restraint in their reaction to the behaviour of the health services providers because most of them are not prepared enough in coming to terms with the disease, much as they have the knowledge and skills. He reinforced his arguments by providing an important extract from Phiri & Webb, a health care provider who argued that:

Health workers are expected to know, feel and act in certain ways. But who has prepared them for this HIV/AIDS? Many health workers have the same information the man on the street has. .... The disease is fatal! Who is not afraid of death? Health workers are in it day in day out. They have not been targeted for any special education program that is relevant to their situation. Knowledge and skills yes, that they have, it is part of many training programs. But what about preparing them to come to terms with their fears and anxieties about their own sexuality and mortality, their prejudices?" (Phiri & Webb Mhonie, Kenya  
(<http://www.hdnet.org/home2.htm>; stigma-aids: health care provider – 17in Brown et al., 2001, p.4)

This argument point to one important area of learning which many training/ educational institutions do not focus much on it. This often forgotten aspect is the area of "attitude change". Many educationists are good at imparting knowledge and skills to their learners, but not attitude. Moreover, this is one of the most important areas which may determine whether an individual will be a successful practitioner in the future or not. In the case of the health service providers, most of them have the necessary knowledge and skills for practicing their work as Phiri & Webb pointed out, but lack the positive attitude of love, tolerance, care, compassion and empathy and yet these are suppose to be part and parcel of any professionals' training as they help in enhancing the persons' knowledge and skills in the area of training.

Other studies by Siegel, Lune, and Meyer, (1998) maintain that in some countries, HIV positive individuals chose to involve themselves in doing constructive activities in an attempt to show the public that they are very normal and able like any other person and therefore are

as productive as any HIV negative person in the community. They also try to show that AIDS is a universal problem and therefore requires a collective solution.

As mentioned earlier, Siegel et al argued that, since men tend to cite the ignorance of HIV-negative people as the primary cause of their discrediting attitudes and discriminatory behaviour in confronting stigma, they sought to alter public attitudes by providing information and offering themselves as examples that defied stereotypes about PWA/HIV. The men hoped, for example, that their life as functional, capable individuals with HIV would serve as a model to challenge the stereotypical image of PWA/HIV as diseased and disabled (Siegel, Lune, and Meyer, 1998). A similar approach has been adopted by some of the HIV positive persons in Kajo-keji County. Some of them involved themselves in doing income generating activities (IGAs) like rearing goats; operating a grinding mill and farming (Coordinator-Ayet).

Weitz (1981, in Meyer et al 1998)) similarly observed that some of the HIV-infected individuals she studied attempted to reduce stigma through the use of a kind of "bravado" in which they tried to refute negative stereotypes and convince others of their continued normalcy through offering themselves as examples of normal functioning individuals. In taking active, socially valued roles as HIV educators, she argued, they strove to offer a positive image which could supplant the popular negative image associated with being a PWA/HIV. The underlying message they sought to convey was that despite the public perception that susceptibility to HIV is virtually limited to marginalized groups; the risk for HIV infection is universal and this message according to her helped to break the "we-they" distinction that allowed some uninfected individuals to define themselves as both safe and morally superior to PWA/HIV (Siegel, Lune, and Meyer, 1998:19). I witnessed a similar approach being employed by the HIV positive persons in Kajo-keji while I was collecting the data for this study. Some of the HIV positive persons involved themselves in sensitization campaign programmes against AIDS in the community. According to Coordinator-Ayet, the leadership of KKLC is trying to encourage all the members of this association of people living with AIDS to participate in these campaign programmes so that they are able to reduce the spread of AIDS among the community members, in addition to changing the community's' negative perceptions against PLHA.

These approaches adopted by the HIV positive persons for fighting stigma have the effect of changing the community's perceptions about those community members who are HIV positive from negative to positive. Though this seems to be a difficult battle to fight, it is a battle worth fighting. This is because the success of these campaign efforts could result in having communities which are relatively free from stigma and discrimination. This also implies that HIV positive persons in these communities may live a fairly normal life with reduced stress levels if any. As stress caused by stigma is seen as the major cause of death among HIV positive persons, then eliminating it also implies eliminating or reducing incidences of AIDS related deaths which also translates to reduced number of children being orphaned by AIDS.

#### **4.1.5. Stigma and discrimination in the church**

However, it is important to note that, despite these negative experiences of stigma and discrimination going on across the South Sudan societies, a lot is being done to counter this trend. For example, the church has tried to organise sensitization workshops to create a greater level of awareness in the religious leaders about HIV/AIDS and at the same time instilling in them the required knowledge and skills for living with the HIV positive members of the society.

Project coordinator-Yesu explained that “we have tried to organise workshops for all our religious leaders right from the level of the lay-readers to the pastors, particularly on the importance of right language use while talking to the church members”. The Catholic Church in Namibia had also applied a similar approach. Aggleton et al (2005) explained that, in 2002, six workshops were conducted for bishops, priests, religious sisters and deacons on how the church contributes to stigma and what can be done to reduce it. As Coordinator-Ayet had argued earlier, during prayers most religious leaders end up offending some of their believers who are HIV positive. According to her, this could be due to a level of ignorance among some of them who think that all the people they are praying with in the church are HIV negative. “What really annoys us is when the pastors in the course of preaching claim that HIV is for sinners and for those with immoral behaviours, forgetting the other ways of acquiring HIV other than sex” (coordinator Ayet).

The available literature on the subject (Asiedu, 2007; Ogden & Nyblade, 2005 and Patterson 1996) indicates that, church leaders across the world have been caught in the same situation



of offending their members due to the kind of language they use. For example Patterson (1996) argued that religious groups may intentionally or inadvertently contribute to discrimination by making explicit or implicit judgements against those who are infected with HIV (Patterson, 1996 in Skinner and Mfecane 2004, p.159). According to Asiedu (2007), “anyone who has HIV is seen as immoral and irresponsible and not fit to be respected or given authority in the church and society (Asiedu, 2007, p.15). Moreover, attempts to label the epidemic as God’s judgement for sinners, especially among prostitutes and drug users have even made the situation worst (Crawrod, Alison, Robinson, Hughes and Samaryil, 1992 & Johnson, 1995 in Skinner and Mfecane 2004, p.159).

Other scholars argue that individuals blame others as a means of getting psychological reassurance. For example, Crewe (1992 in Skinner and Mfecane, 2004) argues that to be able to blame others is psychologically reassuring as it divides the society in to ‘us and them’ as pointed out earlier. Thus, the common saying that, “they are guilty not only of getting themselves ill, but also of infecting innocents” becomes more prevalent. According to Crewe, this practice increases the stigma load borne by those groups seen as responsible.

On a positive note, Project coordinator-Yesu explained that the attitude of some of the religious leaders has to some extent changed after the awareness creation workshops they organised for them. “From talking negatively about HIV positive persons, some of our leaders are now more careful and caring in their words while talking about HIV issues in the church. Some of them have even become close friends to those members of the community who are HIV positive and they now pay regular visits to them”. This practice adopted by the religious leaders in Kajo-keji is similar to the one practiced by the Monks in Thailand. Aggleton et al (2005) argued that, “Monks conduct home visits and demonstrate care towards people living with HIV, providing Buddhist-based counselling and advice on home based care (Aggleton et al 2005, p. 23). Project coordinator-Yesu however commented that this practice has also attracted criticisms from the other members of the church who are HIV negative asking why their leaders were showing more love and care for people who have been living an immoral life. Were they not encouraging them to live the same life?

The change in the attitude of some of the religious leaders has had significant implications on the lives of some of the HIV/AIDS orphans. For example, Religious leader-Yupet explained

that some church leaders have become affectionate to the HIV/AIDS orphans by trying to support them materially and psychologically whenever it is possible. “The main strategy applied for raising money for supporting the HIV/AIDS orphans is by encouraging the worshippers to give offertory during prayers. Though the turn-up of the believers to offer is sometimes very low, we still value the little they give” (Religious leader-Yupet).

On the other hand, the findings of the study revealed that, the little support to the orphans come through the general collection during prayers, but not from the religious leaders as individuals. This is explained by the fact that most of the religious leaders are poor and some of them need support themselves. For example, Religious leader-Salam explained that “we would have helped the orphans because they are really suffering. The problem is that we are also weak. We do not have something to offer. This situation limits our support to only advice and counselling”.

Conclusively, the attempt to challenging stigma and discrimination will face many challenges but as Shapiro (2005) argued, it is important to start from somewhere educating people because:

If knowledge breeds comfort; and, if comfort can promote compassion; then, perhaps, greater compassion from the noninfected community can contribute to a higher quality of life for those persons currently afflicted. (Shapiro, 2005, p.636 in Asiedu, 2007:44)

Compassion, as pointed out by Shapiro is a good attribute which may contribute to promoting the quality of life of the infected individuals. Unfortunately, this is an attribute which is difficult to expect from many community members due to individual difference.

#### **4.1.6. Stigma and discrimination in the community**

Experiences of stigma and discrimination against HIV positive persons are wide spread in Kajo-keji County. As the findings of this study have revealed, there are various ways through which the community stigmatises PLHA. For example, some community members refuse associating with HIV positive persons as revealed by Coordinator-Ayet. As she had pointed out in the findings chapter, some of the HIV positive persons who involved themselves in farming as a way of living positively were chased away from the farm by some of the members of the surrounding community. In addition Coordinator-Ayet and John-Kong of ARC explained that, some of the community members had constantly demanded for the relocation of the HIV positive persons away from the communities within Kajo-keji to an

isolated location between Kajo-keji and Juba counties. These negative experiences by the PLHA have the effect of hindering them from living a normal life due to constant fears and stress.

Moreover, other studies on the same topic within the Sudan and around the world revealed a similar scenario. For example, Christian Aid (2008) in a study conducted in Khartoum, Sudan revealed that, “PLHIV and their families face isolation, insults and shaming. They are verbally abused, secluded from social events, and barred from rented accommodation. In some cases, their children are even refused schooling” (Christian Aid, 2008, p.7). One of the participants in Christian Aids’ study explained that,

I once went to a wedding...when I sat down to eat with them from the same tray, people gazed at me...and then everybody left their hands up and some said: “we don’t want to eat with you...” I left the wedding for fear to cause more embarrassment (PLHIV25, female, age 37 in Christian Aid, 2008, p.7).

Likewise, a study conducted by Perry (2006), in South Sudan revealed that, attitudes that lead to actions such as killing people who have the disease [AIDS] or keeping people isolated are thought to be common. Amongst the Anyuak tribe, such a person would find it difficult to lead a normal life as nobody would dare to get in contact with them. More so, “people returning home from a place known to be a source of sexual diseases may be forced to decide to leave again, even if they are not carriers of any disease” (Perry 2006, p.13). However, it is important to point out that such stigmatisation is not confined to the Anyuak or any one tribe.

To a large extent I agree with all the foregoing arguments advanced by Asiedu, Christian Aid and Perry. What is understandable is that, any human being, whether sick or not, would want to be recognised as a full member of a group through total inclusion in every activity involving the group. However, in a situation where the community members begin excluding an individual amongst themselves, feelings of loneliness, stress and sometimes anger are aroused. Arguably, these feelings become even stronger when the individual suffers from a disease which is believed to have no cure.

Other than isolation, the HIV positive members of the society in Kajo-keji also experience getting of unfair labels against them on disclosing their HIV positive status. For example, project officer-Kudot explained that these members are referred to as “moving graves”. This practice according to Kudot has discouraged many community members from going for HIV

counselling and testing services and those who wish to test sometimes have to cross the border to Uganda, so that the results of the test, are only known to them.

Similarly, Maclean (2004) explained that, in some societies, stigma has been shown to be associated with delays in HIV testing among individuals who are at high risk of being infected with HIV. Even when they get tested, because they fear a positive result, which in their minds is linked to the stigma and social repercussions, they might not return for the results (Asiedu, 2007).

The above scenarios reveal how deeply ingrained HIV/AIDS stigma is among some of the people in South Sudan against the HIV positive members of the society. It has become a normal and yet an abnormal practice against the sero-positive members of the society.

Moreover, as studies by Link and Phelan (2006) among others, and data from Project officer-Deborah have revealed, such practices only add more problems of creating orphans in the community to already the existing problem of loss of resources by the community due to these members' ill health as most of them may not contribute economically both to their families and their communities at the acute stages of the disease, on the one hand, and the expensive treatment costs which have to be incurred by the families of these individuals on the other hand.

#### **4.1.7. Schools as “safe havens”**

The HIV infected and affected members of the society in Kajo-keji County of South Sudan do not only find protection, care and love from the religious institutions alone, but from the educational institutions as well. The findings of this study revealed that some schools in Kajo-keji county of South Sudan have become ‘safe-havens’ for the HIV affected children as they are virtually the most peaceful places where the HIV/AIDS orphans can stay without experiencing stigma and discrimination. For example, most the teachers and the learners in the schools who were part of the study contend that schools are safe havens for both the HIV infected and affected children where stigma and discrimination does not exist.

The school administrators explained that they have created an inclusive culture and policies in their institutions which create a conducive learning environment for every pupil. Deputy Head Teacher-Malual backed this general argument by explaining that “HIV/AIDS is like

any other disease these days, and it is not for specific people but it is for all”, signalling to all the members in the institution that even though there are pupils who are HIV positive in the school, their presence shouldn’t be a source of discussion to the other members because it is not something special. It is what any other member of the society can acquire any time like the case with malaria, and any other disease.

To me, this is a very good approach to countering stigma and discrimination practices in the schools, which can be applicable in other settings as well for example in the community where stigma and discrimination is quite prevalent. Moreover, the teachers and the pupils interviewed in the schools offer similar arguments to that of the Deputy Head teacher-Malual in regards to existence of stigma and discrimination in the educational institutions in Kajo-keji County, South Sudan. In the findings chapter, Teacher-Lokutuk and Head Teacher-Golyan were quoted as stating strongly that they did not believe that stigma and discrimination exist in their schools because according to Lokutuk, “discrimination is due to lack of education on HIV/AIDS”. He added that HIV/AIDS is not like tuberculosis that one can contract through the air. This argument seems to suggest that this school has done a lot of work in imparting HIV/AIDS knowledge to its learners. Similarly, Head Teacher-Golyan of Hope primary school exclaimed, “Stigma here? Within the children? Haaa! I have not seen. Maybe in the community where we don’t know, but within here? No.”

Nyaret, a 13 years old HIV/AIDS orphan explained that, “I do not think that stigma and discrimination exist in our school because no pupil has said anything bad to me for all these years I have been here”. Throughout my interviews with the rest of the HIV/AIDS orphans, this was the view I was getting from all of them which gives one a reason to agree with the teachers’ arguments on the issue. More so, throughout the two months period I have been in these schools interacting with both the teachers and the pupils in and outside the class rooms, it has been very difficult to practically observe the difference between the HIV/AIDS orphans and the other pupils particularly during the social hours, though the distinction is quite prevalent between them in areas like possession of scholastic materials, school uniform and payment of school fees as it was possible to see most of the orphans wearing torn clothes, not writing in the class due to lack of writing materials or sometimes being chased home for having not paid school fees.

I need to clarify that, over all, because of the efforts made by the school authorities in creating an inclusive environment for all, there was thus no direct discrimination against the HIV/AIDS orphans, but also, there was no consideration of their situation as special. However, an important thing to emphasise here is that, despite this relatively inclusive environment for the HIV/AIDS orphans in the Schools, the same is not true for them both at home and in the community generally as outlined earlier. As Coordinator-Ayet had elaborated, in the hospital, the HIV positive members of the society are referred to as “foxes” and in some instances, they are referred to as ‘rotten people who do not deserve wasting medical staffs’ time; in the church they are seen as ‘sinners, immoral and responsible for their suffering; while in the community, they are referred to as ‘moving graves and dangerous’. Some members of the society advocate for their relocation to a distant and isolated location. This context leaves only the schools as ‘safe havens’ for the HIV/AIDS orphans because of the relatively inclusive environment their heads have created for these children by ignoring their connection to HIV/AIDS.

The actions of these heads of institutions are in line with the convention on the rights of the child (1989), which seeks to ensure that; the right of all children not to be discriminated against when receiving education are respected.

It is in line with this convention that some educational institutions like UNESCO are taking the lead in promoting inclusive education across the world. Through development of educational materials, organising of conferences and meetings, UNESCO has managed to draw the attention of many educational stakeholders around the world to ensuring that all children regardless of their background, social status and physical conditions are provided with the opportunity of acquiring education in an environment which is accommodating of all their needs. Though this totally accommodative environment is not yet achieved for the HIV/AIDS orphans in South Sudan, the actions taken by the fore-mentioned heads of institutions are positive steps to achieving it.

According to UNESCO (2003), inclusive education means that, schools should accommodate all children regardless of their physical, intellectual, social, emotional, linguistic and other conditions. This should include HIV/AIDS children, disabled and gifted children, street and working children, to mention but a few. Save the Children (2002) on the other hand defines inclusive education as “a process of increasing the participation of all learners in schools [including those orphaned by AIDS]. It is about restructuring the cultures, policies and

practices in schools so that they respond to the diversity of learners in their locality” (Save the children, 2002, p.9). It further argues that, flexible, quality and responsive learning environments will benefit all children and are fundamental to including marginalised groups like the HIV/AIDS orphans in education. Two important characteristics of inclusive education are worth mentioning. It acknowledges that all children can learn, and, it respects differences in children in regards to age, gender, and ethnicity, language, disability, and HIV status.

Moreover, UNESCO, (2009) argues that, inclusive education is a process of strengthening the capacity of the education system to reach out to all learners and can thus be understood as a key strategy to achieve EFA. This argument is very important in that, it has some implication for the education system in South Sudan. In reference to the foregoing, it is then arguable that, if the capacity of the education system in South Sudan is strengthened, then the likelihood of many schools becoming ‘safe havens’ for HIV/AIDS orphans is increased, hence paving a way for the EFA goal of universal access to education by all children in the country.

Over all, it is important to acknowledge that, the role of the educational institutions in fighting stigma and discrimination should not be underestimated. In related studies around the world, it has been revealed that schools have played a significant role in fighting stigma and discrimination among the members of these institutions and in some instances, extending this role outside the schools to the general community. In neighbouring Uganda for example, the ministry of education and sports adopted the multi-sectoral strategy for combating AIDS. This strategy ensured that every sector in the Ugandan society must get involved in combating AIDS and particularly the stigma and discrimination associated with it. In this respect, the media, NGOs, FBOs, CBOs and the educational institutions were all involved in the campaign for reducing if not eradicating stigma and discrimination in the Ugandan society. In the education sector particularly, this strategy was implemented in such a way that no educational level is left unattended.

In order to achieve this, the school administrators and teachers were tasked with the role of counselling. Nsubuga and Jacob (2006) explain that, the school administrators and senior male and female teachers have to serve as counsellors to students about HIV/AIDS issues. They maintained that this counsellor-patient relationship is important especially when

students learn for the first time that they are HIV positive. Other than the school administrators and the teachers, the teacher training institutions were actively involved in preparing the next generation of teachers with adequate information and life-skills to help integrate HIV/AIDS information into their classes (pp.36-7). In order to ensure that every teacher acquire this knowledge and skills, in-service training seminars were regularly organised for the teachers by the MOES. This on-going strategy is intended to ensure that the existing primary and secondary level teaching force is well-equipped with prevention, counselling and treatment of HIV/AIDS knowledge and skills.

Nsubuga and Jacob (2006) further argue that, because of the sensitive nature of discussing sexual matters in schools, peer education forums were often an effective avenue for the dissemination of information. In addition, anti-AIDS students clubs were formed to provide students with the opportunity to discuss sex education issues among friends and peers. They further explained that, although HIV/AIDS has not been part of the national curriculum in Uganda, the PIASCY programme emphasizes the integration of HIV/AIDS information as a fundamental part of primary and secondary education level curriculum. They clarified that at the secondary education level, HIV/AIDS is being integrated into five key subjects already being offered to students.

Other than integrating HIV/AIDS information into the curriculum, Nsubuga and Jacob (2006) maintain that school-wide assemblies were/are hosted on a bi-monthly basis where key issues are discussed about the nature and prevention of the disease. The last strategy was to ensure that Handbooks and other ICE materials are made available for teachers and students to provide age appropriate information to them. It is important to remark that because of this multi-sectoral approach adapted to fighting AIDS and particularly AIDS stigma in Uganda, the Country has been and is still seen as a model in Africa for its proactive approach to fighting AIDS and its associated stigma. Nsubuga and Jacob argue that these and other factors are what explain the reduced existence of stigma and discrimination in Ugandan educational institutions. Similarly in Zambia, Aggleton et al (2005) argue that schools provide training to teachers and young people through the schools' anti-AIDS clubs which were significant in reducing stigma and discrimination.

In reference to the foregoing, I argue that, though some schools are already being seen as "safe- havens" in South Sudan where HIV/AIDS orphans can enjoy an environment relatively free from HIV/AIDS stigma and discrimination, still more work needs to be done. This is



because comprehensive policies at national level in South Sudan for combating HIV/AIDS stigma and discrimination in educational institutions are still non-existent. However, with the south of the country having voted for separation from the rest of Sudan on 9<sup>th</sup>, January, 2011, and the expectation that it is to become a fully independent state by 9<sup>th</sup>, July, 2011, the hopes are very high that much more will be done in the education sector with regard to development of a multi-sectoral strategy for combating AIDS and its associated stigma in the new country.

This optimism exists for a number of reasons. The new state will be governed more on secular values which recognise the freedom of every citizen. With this in mind, HIV/AIDS will be accepted as part of the development challenges facing the new nation requiring appropriate solutions. More so, the new nation will have the freedom to allocate the necessary resources within its reach to addressing its national issues. Important to achieving the above will be the new country's' focus in addressing the capacity gaps among its citizens which have acted as hindrance to implementation of many development initiatives previously. With this in mind, then it is expected that the level of the population awareness about AIDS is going to increase, hopefully resulting in reduced incidences of HIV infection among the population.

This first part of the discussion chapter on stigma and discrimination can now be concluded by arguing that AIDS related stigma poses a problem for all in the society, thereby imposing severe hardships on the people who are its targets and it ultimately interferes with treatment and prevention of HIV infection. Emphasis on the eradication of AIDS-related stigma would enable the creation of a social climate conducive to rational, effective and compassionate responses to this epidemic. Moreover, creation of an inclusive learning environment by educational institutions is expected to increase orphans educational achievements. More so, eradication of AIDS stigma will play a significant role in creating a conducive environment for the HIV/AIDS orphans thereby increasing their ability to socialise and interact freely beyond the school.

#### **4.2. Part two: Coping strategies**

This second part of the discussion chapter attempts to answer the second part of the research question which asks about the coping strategies the HIV/AIDS orphans have developed, both on their own and with the help of stakeholders for dealing with their educational-related challenges. As presented in the findings chapter, these orphans face numerous challenges ranging from the inability to raise money for paying their school fees, to a lack of food,

medical care, scholastic materials and parental love and care. However, it ought to be noted that these challenges are not of the same degree. Some seem to weigh on them more than others and this has been expressed to the researcher in different ways, by all the participants involved in the study. It was noted that the inability to raise money for school fees seem to be the most difficult challenge faced by almost all the HIV/AIDS orphans, while a lack of scholastic materials like exercise books and pens seem to be the least felt challenge. This could be explained by the fact that UNICEF and other education implementing NGOs sometimes distribute free scholastic materials to the pupils in the schools across South Sudan.

Overall, the financial challenge still remains the most difficult challenge faced by the HIV/AIDS orphans as expressed by my research participants. For instance, from all the stakeholders and orphans interviewed, it has been more common to get expressions like, “my major challenge is lack of books and the payment of my school fees...” (Taling, a 15 years old primary six pupil in Hope primary school). More so, Coordinator-Ayet who works directly with the HIV/AIDS orphans argued that “the main challenge is lack of support in terms of education and in terms of other requirements also like clothing, food and other needs...”. Teacher-Phiri & Webb who is more of a parent to the HIV/AIDS orphans in the school explained that, “most of the challenges they face are related to payment of school fees ...” and Teacher-Milyan put the argument more broadly that, “to me, let me say, the biggest challenge is the fact that they have no scholarship and when they are sent home because of having not paid, so they become psychologically tortured...”. Yaba, a manager in an orphanage centre was more direct in his argument and pointed out that, “the major challenge these orphans face is in the area of getting school fees ...” Head Teacher-Golyan seems to be summarising the arguments of the rest of the participants when he explained:

Yaa of course, if a child has not got a very good guardian definitely he/she will experience some problems. Like one of the problems which you must have already experienced, -payment of school fees. Is very difficult; particularly if this guardian is a woman, it is very difficult. So school fees payment is the other biggest challenge.

However, a very important question to ask is: what do the above expressions translate to or mean in the daily lives of the orphans? Suggestively, it seems possible that the financial challenge is viewed by all the stakeholders interviewed and the HIV/AIDS orphans as ‘the biggest challenge’. Though expressed in different ways, at least every stakeholder including the HIV/AIDS orphans have expressed difficulty in getting money for their school fees,

referring to it as their 'biggest challenge'. A study conducted in Uganda by Ntozi titled 'effect of AIDS on children' also came up with the same conclusion (Ntozi, 1997). The challenge of getting exercise books is the least mentioned, meaning that though it is still a challenge, its effect is not as much as that of school fees and other needs.

These findings seem to be in agreement with that of a recent study conducted in the same research area about the needs of orphans and most vulnerable children (OVCs) in Kajo-keji County, South Sudan. The study entitled "OVC Needs Assessment, Kajo-keji County" conducted by the South Sudan AIDS commission (SSAC) in July 2009, had many objectives among which are to establish the community perception and attitudes about vulnerability according to priority. It sought to establish community perceptions of the major needs of OVC and establish approaches/interventions that communities are already engaging in to support OVC. The study wanted to understand what orphans and vulnerable children consider as their major needs in order of priority and the different approaches that they feel would be helpful in responding to some of these needs.

The findings of the study show that HIV/AIDS orphans, both double and single are the most vulnerable and the need to access and acquire quality, lifelong education ranked the highest. The other immediate need that followed the need for education, and in agreement to the findings of this study, are shelter, clothes, shoes, food, health care, counselling support, including care and guidance (SSAC, 2009; UNICEF, 2008). From the foregoing, 'the education need' has been established to be the most prioritised and yet the most difficult to acquire due to the financial limitations of most orphans and guardians.

It is worth noting that orphans enrolment and retention in school has been greatly affected due to the current practice of charging school fees in almost all schools in South Sudan. Though the GoSS Ministry of education, science and technology (MOEST) policy indicates that basic primary education in South Sudan is free (MOEST/GoSS, 2006), this is actually not what happens on the ground as some charges still exist. These include parents-teachers association (PTA) contribution, development fee, registration fee and examination fee. Though the total amount required per child per term is quite affordable for a working adult with good and regular salary, this is not always the case with most families which are not employed in the formal sector. More so, even some of those South Sudanese employed in the formal sector like primary school teachers find it difficult to afford paying that cost due to the practice of having an extended family system and hence too many children to support.

A study conducted by UNICEF/GoSS in 2008 revealed that over 70 % of the parents in South Sudan view the cost of education as too expensive for them to afford (UNICEF/GoSS, 2008). This spells a great risk to the education of the HIV/AIDS orphans whose educational needs may not be prioritised by most guardians with whom they live. Most of these guardians may prioritise the education of their own children first to that of the HIV/AIDS orphans who are after all viewed as an additional burden to them (Subbarao & Coury 2004). In line with this argument, Ntozi & Mukiza-Gapere (1995) maintained that “it is logical to expect that, a much higher percentage of orphans was not going to school since they take second place to the parents’ own children in priority for education” (Ntozi and Mukiza-Gapere, 1995, p.249).

A further analysis of the field data showed that the girl child who is an HIV/AIDS orphan in South Sudan faces more challenges than the boy child in the same category. As was shown in the findings chapter, though boys like Lomole, a primary three pupil in Hope primary school, undergo very difficult situations in relation to meeting his basic material needs like money, food, clothing and medicine; considering the fact that it was practically impossible for him to go to school or get his daily meal unless he has sold some water to the restaurant owners, the girls on the other hand have to shoulder extra burden in addition to the general challenges stated above. For example, the elderly girls in most cases have the responsibility of taking care of their siblings in the event of the loss of their parents to AIDS or when their parents are already in the acute stage of the disease. Practical examples of this scenario in this study are HIV/AIDS orphans like Pitet and Yatet who have to come in to fill the gaps left by their mothers’ deteriorating health conditions and death respectively.

I have tried to illustrate their situations in chapter three through Yatet, for example, who explained how worried she is about her mothers’ deteriorating health condition; where all the time, she is very busy working, cleaning and cooking for her siblings. Gradually, she realised her grades have gone down as these domestic duties were not giving her any opportunity to revise and do some home work which are an important part of her self-study.

Moreover, the situation is not very different for Pitet, a 16 years old HIV/AIDS orphan in Liberty primary school who explained that:

My sick father does not want to hear me telling him about any of my school needs like school fees, uniform, paraffin, books and pens. He informed me that ‘let me suffer the way he had suffered’. Because of my interest in school and since there is nobody I can go to for help, I decided to do some small income generating activities

like selling water, pan cakes, mangoes and cassava flour. Sometimes, I dig for other people for money. All these activities help me to remain in school, but take much of my time for studies and now I am no longer performing well in school, particularly in mathematics. Moreover, all the domestic work at home is entirely shouldered by me (Pitet, a 16 years old orphan in Liberty P/S).

As can be seen, the extra burden placed on the girl child has had the effect of declining school performance. Both girls explained in further detail how they have to struggle to raise the necessary resources for meeting their own and their siblings' basic material needs for keeping them in school and maintaining them alive at home. They spoke of how, during weekends, holidays and after school hours, they have to engage themselves in selling water, pan cakes, mangoes, cassava flour and doing farm work for some people who could pay them money. These numerous activities seem to leave them with only little time for themselves, and yet they are still children who need time to play, socialise and revise their school work. Moreover, they are emotionally burdened by their parents deteriorating health conditions. All these have negative effects on their school performance and eventually reducing their prospects of continuing with their education.

Moreover, this scenario is not unique and not only typical of South Sudan HIV/AIDS orphans. Other studies conducted around the world on the same target group revealed similar results (Phiri & Webb, 2002; Foster & Williamson, 2000; Germann, 2005; Kelly, 2000; Moletsane, 2003 in Zondi, 2006; Ntozi 1997; Ntozi and Mukiza-Gapere, 1995; Subbarao & Coury, 2004; Togom, 2009 and UNESCO, 2010); For example, Togom, (2009) in a study entitled 'Challenges facing AIDS orphans in Nairobi Kibera slums; argued that " AIDS orphans especially the girls heading their households are the most vulnerable to various kinds of problems and they are over burdened by shouldering adults' responsibilities of care giving to the siblings and other members of the family" (Togom, 2009, p.i). The UNESCO's Global Monitoring Report, entitled 'Reaching the marginalised' backs Togom's argument and explains that in most countries around the world and more particularly in Sub-Saharan Africa, the girl child is the most affected by the effects of AIDS in the family as most of them have to engage in doing income generating activities (IGAs) for earning a living and supporting their siblings. This has had the effect of declining performance of the girl child in school and in the worst case scenario, dropping out from school completely in order to support their siblings and the sick members of the family (UNESCO, 2010).

In other related studies, Moletsane (2003) in Zondi (2006) argued that, the girl child had to take on the role of caring for ill people or their siblings in the absence of their care givers. She explained that, “there was a practice of non-payment of their fees in favour of boys in the family” (p.10). She raised her arguments to another level by arguing that, “this burdening of the girl child with these domestic duties was not only as a result of the absence of the adult care givers, but as a result of stereotypes embedded in the belief system of the community which holds that the girls’ place is in the home” Zondi, 2006, p.10).

This implies that, the problem for the girl child does not only stem from the fact that most of them lack adult care givers because of losing them to AIDS, but from some belief systems embedded in some communities too, which continues to assign the main care-giving roles to females. This has the effect of putting the girl child on too much pressure of doing domestic work while the boy child has the freedom of either playing with friends or revising his school work.

These beliefs systems are still prevalent across most rural areas in Kajo-keji County. Typical examples of girls who have fallen victim to these belief systems are Pitet and Yatet respectively who are both participants in this study. These girls wake up at 5: 00 am in the morning, and begin their day by doing domestic chores like fetching water, sweeping the compound, washing utensils and preparing breakfast for the whole family. They do all these activities while their brothers are still enjoying their sleep in bed or preparing for school. The boy child is then invited to come for breakfast and both go to school. As they return from school, it is the responsibility of the girl child to plan what to cook for the family. These girls explained to me that, less than half of their time at school is used for thinking about academic issues as they always have to spend much of their time reflecting on what to cook for the family in the evening when they return home, while for the boy, his mind is all focused on his academic work. As evening falls, the boy child is free to go to bed or for revisions after meal, but the same is not true for the girl child as she has to put everything in order before she goes to bed, when practically she is already too tired to open her books. As weekends come, it is the girls who are more involved in doing leja-leja for raising money for their school fees and in some cases, that of their brothers too. In a nutshell, the culture places the girl child in a very difficult position which makes it hard for her to concentrate in school. When this

practice continues unchecked, the expected result is a declining school performance of the girl child and eventually dropping out of school.

In agreement with Zondi's argument, Kelly (2000) adds the element of the rural situation and argues that, "when demand for education falters, the first one to be negatively affected is the girl, but above all, the girl in the rural setting" (Kelly, 2000, p.53). He argues that across many societies, if there are problems in meeting the cash cost of education, a boy will be favoured in preference to a girl and this is because many societies consider that, a girls' primary role is caring for the home (Kelly, 2000). These arguments are quite relevant to South Sudan and Kajo-keji County in particular where this study was conducted, considering the fact that it is still more of a rural society. A typical example closely related to this scenario is Pitets' relationship with her father. Whether he is financially incapacitated or not is still another issue all together, but the way he responded to the daughters' request for school fees (you suffer the way I had suffered) seems to show that he is disinterested in supporting his daughter educationally.

#### **4.2.1. The concept "coping"**

Ebersohn and Eloff (2002) argue that, at its most basic conception, "coping implies adaptation by an individual to demands" (Ebersohn and Eloff, 2002, p.79). To them, coping is a process of interaction between an individual and an environment, each with its own set of resources, vulnerabilities, potential and needs. I will explore the "individual" and "environment" elements of the definition further.

The above arguments imply that, the environment from time to time exerts some demands or pressure on the individual. In the individuals attempt to adopt and survive in the given environment, he or she has to develop some strategies to cope with these demands. This is the situation the HIV/AIDS orphans in Kajo-keji County of South Sudan found themselves in. Most of them found themselves in a hostile environment right in the early stages of their lives. An environment without biological parents and caring guardians and an environment where close relatives reject them from living at their homes. In addition, it's an environment where the bare minimums of love, care and protection hardly exist and where surviving parents shout at their daughters "you suffer the way I had suffered" (Pitet) and uncles tell their nephews; "do not disturb. We were not the ones who had asked your father to

misbehave and contract AIDS” (Yatet) and yet, there is no better environment for them to go to other than this.

Coping with these multiple demands became the only solution. Those unable to enrol in school have to struggle for their survival by adopting the leja-leja coping strategy where they employ their labour to get their daily meal and for those who have succeeded in enrolling at school, have to struggle to meet their survival needs at home and at the same time, work harder to meet their school needs.

Overall, the HIV/AIDS orphans do not only face the material challenges from the environment they find themselves in, but the emotional challenges too as most of them do not have parents who can provide them with love, care, warmth and affection in times of need. As was noted earlier in this chapter, many of them, like Yatet, are broken-hearted because of the deteriorating health conditions of their parents. In short, as Ebersohn and Eloff (2002) argued, coping is what people do when they successfully manage transactions with their environment.

On the other hand, Ebersohn and Eloff (2002) argued that coping is acquired by learned adaptive actions. They added that much as children are unique individuals, they still learn by following examples of significant others like parents, aunts, grandmothers, older siblings, teachers and social workers who guide them in developing coping options.

Though I agree with the above assertion to a large extent, it is still arguable that the above theory is not universally binding as it seems to suggest that children do not cope on their own, implying a high level of children’s dependence on significant others. The findings of this study seem to suggest that, in very difficult situations, children can cope on their own without much support from significant others. In reference to my participants, it is arguable that most of the coping strategies they developed can be referred to as “survival strategies”, which tend to emerge instinctively and at times creatively without directives from significant others. In this case, the orphans only have very limited options in a way that they either do leja-leja in the form of fetching water for sale, digging for other people or looking for local herbs in order to get their daily food, treat illnesses and go to school or they sit idle and remain without schooling, suffer from hunger, illness or die in the worst case scenario.

However, I fully agree with Ebersohn and Eloff’s, (2002) concept of a transactional coping process. According to this theory, the environment makes constant demands on the individual



as explained in the first part of this section. The individual experiences these demands as stress in the form of anxiety and tension (Ebersohn and Eloff, 2002, p.80). This forces the individual to decide on how to manage the stress. The outcome of the decision – making is either coping positively or negatively. For example, if an individual decides to get involved in doing some work which will enable him or her to get a long term solution to the stressors, like selling of water, pan cakes, mangoes or digging, then that is positive coping. However, if the individual decides to go for begging or stealing from the neighbour, then that is negative coping as the solution it provides is short term and might lead to more stress. At this point, it is important to ask this vital question: ‘How do children cope?’

Ebersohn and Eloff (2002) developed another concept on how children cope. According to them, “children's coping equals the integration and application of developmental skills like motor control, communication, cognitive and socio-emotional skills into their daily living” (Miller & Byrnes, 2001; Zeitlin & Williamson, 1994, cited in Ebersohn & Eloff 2002). They argued that one primary developmental task in childhood is to transform early adaptive behaviours into mature coping styles (Masten & Coatsworth, 1998; Salovey & Sluyter, 1997, in Ebersohn & Eloff 2002). They explained that, in their initial dependent life phase, children's transactions are more reflexive and universally undifferentiated – crying, cooing and sucking. Children's motor, affective, and cognitive skills are refined as their central nervous systems mature and they acquire experiences in the environment. Their explanation also points to the importance of stress. They argue that, the presence of stress is natural as it creates tension and motivates a child to develop by interaction with the environment, hence, enabling them to cope. Thus by learning to cope, children gradually gain more autonomy and independence (Ebersohn & Eloff, 2002). As experience has shown, many children who have never experienced stressful situations at their early age will fail to cope when confronted with them at a later age. Therefore, much as excessive stress may have some negative effects in the body with disastrous consequences (Asiedu, 2007; Link and Phelan, 2006); when controlled and managed well, it helps in strengthening individuals (Ebersohn & Eloff, 2002).

It can therefore be argued that the stress created in the HIV/AIDS orphans by stressors like death of parents, attending to sick surviving parents, caring for younger siblings, lack of money, food and medicine is what might have motivated them to develop practical coping strategies like doing leja-leja in the form of selling water, mangoes, pan cakes and the use of local herbs in order to cope with the educational-related challenges they face.

Ebersohn & Eloff (2002) also related their coping theory to the resilience theory developed by Kilmer, Cowen & Wyman, 2001; Garmezy & Rutter, 1988 cited in Ebersohn & Eloff, 2002) which states that, “children should have access to resources both internal and external to cope effectively – to change what they can, or make the best choices regarding things they cannot change” (Ebersohn & Eloff, 2002, p.81). In relation to the coping strategies developed by the HIV/AIDS orphans in Kajo-keji county, south Sudan, the presence of natural, readily available resources like the mangoes, water and local herbs helped some of them to cope with their educational–related challenges.

The next section is devoted to discussing the various coping strategies the HIV/AIDS orphans have developed for dealing with their education-related challenges. This will be followed by a discussion of how the various stakeholders have helped the HIV/AIDS orphans cope.

#### **4.2.2. The leja-leja and other coping strategies**

The leja-leja coping strategy developed by the HIV/AIDS orphans is what has enabled some of them to remain in school to date. It involves a total commitment from the HIV/AIDS orphans to addressing their own challenges with minimum assistance from either the significant others or the other stakeholders. This has to do with involving themselves in doing income generating activities like selling water, pan cakes, mangoes, and doing farming work for some people in order to raise money for paying their school fees and acquiring scholastic materials. Discussing another context, Germann (2005) explained that some of the Zimbabwean HIV/AIDS orphans had to involve themselves in doing income generating activities as well in order to raise money. While others sought school fees support from churches and some like the older siblings chose more drastic options like “leaving school in order to keep younger ones in school” (Germann, 2005; Subbarao & Coury 2004). In addition, some have to exploit the gifts of nature for addressing their day to day health challenges through the use of local herbs for the treatment of various illnesses.

Apart from the leja-leja coping strategy, which most of the HIV/AIDS orphans use for meeting their financial needs, some of them have to cultivate around their homesteads to sustain themselves. For example, Pitet, one of the HIV/AIDS orphans explained: “We have a garden near our home which I, together with my younger brothers, cultivate in order to produce food for our survival”. These food/nutrition coping strategies developed by the

HIV/AIDS orphans in South Sudan are similar to the ones developed by other HIV/AIDS orphans in Sub-Saharan African countries. For example, Germann (2005), in his study of HIV/AIDS orphans in child headed households in Zimbabwe found that most HIV/AIDS orphans involved themselves in “growing food on their own yard, visiting neighbours for meals, hiring own labour for food and asking neighbours for food support” (Germann, 2005, p.411).

Emotionally, the HIV/AIDS orphans in Kajo-keji County, South Sudan, have to seek the assistance of elders and religious leaders for counselling services in stressful moments. For example, Yaba, one of my key informants in the study explained that he has to regularly do both group and individual counselling for the HIV/AIDS orphans under his care and this mainly depended on the kind of challenges the individual orphan faces. In the same way, Germann’s (2005) study of Zimbabwean orphans showed that they also had to seek counselling support from elders and church leaders, while others addressed their emotional challenges by sharing their problems with their fellow orphans and peers.

However, it ought to be noted that, while some of the orphans are able to develop positive coping strategies like the ones discussed above, others adopted negative coping strategies which are rather risky and some do not offer long term solutions to their challenges. Though this study did not identify similar situations in Kajo-keji County of South Sudan, elsewhere in sub-Saharan Africa and particularly in Southern Africa, studies show that orphans often do not cope with their challenges positively. For example, Germann’s (2005) study of orphans in child headed households show that some of them engaged themselves in activities like prostitution in order to cope with their financial and food challenges. Similarly, Subbarao and Coury (2004) explained that evidence from South Africa and Namibia suggests that, in some extreme cases, orphans who live on the streets are exposed to prostitution, HIV infection and crime.

Togom in his study of challenges facing AIDS orphans in one slum area in Kenya explained that, orphan children described their coping mechanisms as ranging from leaving their own original homes and lives due to abuses and stigma, to seeking aid from institutions, relatives, community and parent’s friends. Compromising education to seek income generating activities, engagement in risky behaviours like prostitution, combining of work with school

leading to interruption of regular school attendance are some of the coping strategies they developed (Togom, 2009). All these contributed negatively to their school attendance and performance though it has enabled them to survive or earn a living (Subbarao & Coury 2004).

Mainly two reasons explain why the orphans in my study have not resorted to negative coping strategies. The strong religious environment they found themselves in is one such important reason. For example, throughout my period of the study, I have been observing a routine practice of prayers in both schools. This prayer was organised by both the school administration and the religious institutions around the school. At the school, there is the compulsory Morning Prayer every day before the start of lessons, while on Wednesdays and Fridays every week, the religious leaders from any of the churches or mosques were invited to come and conduct a religious service with the pupils. In every preaching, strong emphasis was made on upholding morality among the pupils in addition to encouraging the pupils to be hard working and God fearing.

The second important area to discuss in regards to some of the coping strategies which have enabled some of the HIV/AIDS orphans in Kajo-keji County, South Sudan to cope with their challenges has to do with the role NGOs, FBOs, CBOs, CSOs and the community at large play in helping the HIV/AIDS orphans cope with their education related challenges. The data collected for this study show that some governmental and nongovernmental organisations like IGAD, UNICEF, JRS, ARC, SSAC and some FBOs and CBOs like KKLC, ECS and KAP have played a significant role in facilitating the coping process of the HIV/AIDS orphans. For example, IGAD through SSAC and KKLC are currently helping in paying the school fees of 80 HIV/AIDS orphans in Kajo-keji County of south Sudan, meanwhile UNICEF and JRS are credited with the crucial role in supplying most schools in South Sudan with scholastic materials and some of the CBOs and CSOs like KAP mainly play a lobbying and advocacy role which has enabled many people in the country to know about the plight of the HIV/AIDS orphans in South Sudan. FBOs mainly play an instrumental role in offering counselling services and support to orphanage centres which are home for most of the double orphans.

However, it is important to note that, though orphanage centres are good because of some of the services they offer to the HIV/AIDS orphans like provision of shelter, food and education

services, they also have their own short falls. Some studies conducted to assess the suitability of orphanage centres concluded that overall, the demerits of keeping an orphan in an orphanage centre are more than the merits. For example, (Phiri & Webb 2002) argues that, while orphanage centres may provide some of the ‘nurture’, typical institutions do not provide the holistic care that children are entitled to for all round development. This is because, children in institutions lack basic and traditionally accepted social and cultural skills to function in their societies; they have lower levels of educational attainment; have problems adjusting to independence after leaving the orphanage, lack basic living skills; have more difficulties with relationships, lack parental skills and some of them often have a misplaced sense of entitlement without a parallel sense of responsibility (Phiri & Webb 2002).

Furthermore, children in institutions have tenuous cultural, spiritual and kinship ties with families, clans and communities the report claims. These ties are especially critical in Africa and Asia as they are the basis for people’s sense of connectedness, belonging and continuity. They are the basis upon which life skills as well as social and cultural skills are attained. In addition, children raised in institutions struggle to be accepted or fit into traditional rituals and ceremonies.

In some studies carried out on organisations involved with orphans, around the world, it was found that, both governmental and nongovernmental organisations including the faith based organisations and the community based organisations have been fully involved in supporting the HIV/AIDS orphans in areas like care and support, guidance and counselling, home based care and education (CAPA, 2007). In a study conducted by Michael Fleshman in 2001 in Zambia, he explained that organisations and the community are reported to have developed three types of responses to the orphans’ problems due to the governments’ financial problems. The first is to lobby local school management committees to waive fees for the most vulnerable children. The second community strategy is to raise money for orphans’ school fees and this collection is provided to the neediest as bursaries, and the third approach was the open community schools programme. In this programme, community schools without fees or dress codes were created for the most vulnerable children. More so, volunteer teachers were used to offer services and the first six years curriculum in primary school was condensed to three. Over all, this community approach to solving the orphans’ problems in Zambia played a significant role in keeping these children in school and at least enabling

most of them to acquire basic primary level education. The open school initiative particularly triggered a rapid increase in the orphans' attendance, though as Fleshman noted, this rapid increase was at the cost of reducing education quality. In addition, the waiving of the school fees weakened the schools' financial positions since their income base had been tampered with.

Aggleton et al (2005) in a related study conducted in the catholic diocese of Ndola in Zambia explained that, in its attempt to alleviate the conditions of the orphans, the diocese "provided support to orphans in the form of school fees, and nutritional support, as well as linking and making referral services to other orphan support programmes" (Aggleton et al (2005, p. 18).

It is therefore important to note that though similar initiatives have been started by some communities in South Sudan, much has not yet been achieved. The success so far reported is the attempt by community leaders like Yaba in convincing school head teachers not to send orphans home for having not paid their school fees. Thus, it is worth noting that, though this act seems insignificant, it may be a good beginning as it has the effect of encouraging other community leaders to do the same in the future.

On the other hand, this study also found that the government of South Sudan and the teachers who are expected to play a significant role in helping the HIV/AIDS orphans to cope with their education-related challenges are not doing enough. Most of the directors interviewed in this study explained that the South Sudan government has not been able to extend the much needed financial support for HIV/AIDS orphans and most directors attributed this failure to the infancy of the government. However, other stakeholders attribute the failure to capacity gaps and shortage of skilled personnel both in the ministry of gender, social welfare and religious affairs of the government of South Sudan and SSAC (UNGASS, 2010). The teachers attributed their inability to support the orphans to the low salaries they get which in most cases are irregular. The next section is devoted to discussing the attitude of the teachers and uncles towards support to the HIV/AIDS orphans.

#### **4.2.3. The attitude of uncles and teachers towards support to HIV/AIDS orphans**

Most of the teachers interviewed in this study explained that they have not been able to support the HIV/AIDS orphans cope with their financial challenges because of the difficult conditions surrounding them and most importantly, the work environment and the terms and conditions of their work. According to this group, their salaries are low and irregularly paid and yet the cost of living in South Sudan is high. This, they say, makes it very difficult for them to meet their own personal and family needs. The implication of this is that their ability to extend support to children other than their own is weakened. However, this is not considered as a genuine reason in most South Sudanese societies for not helping a needy person as our cultures place more importance on sharing whatever little one has with the needy. In reference to the foregoing, it can therefore be said that these practices may be regarded as foreign as they are inconsistent with the local beliefs and practices traditionally held by the people of South Sudan and Africa in general. As Archbishop Desmond Tutu once said,

In our African idiom, we say, “a person is a person through other persons.” None of us comes into the world fully formed. We would not know how to think, or walk, or speak, or behave as human beings unless we learned it from other human beings. We need other humans in order to be human. The solitary, isolated human being is really a contradiction in terms (Tutu, 2000 in Asiedu, 2007:45).

A critical reflection of the whole scenario forces one to question whether such behaviour can be attributed to modernity or development of modern attitudes among the teachers in this newest Country on earth. A further discussion on this issue will be taken up in chapter five.

#### **4.3. Conclusion**

This chapter discussed and analysed the findings of the study which was aimed at explaining education-related challenges faced by HIV/AIDS orphans and how they on their own and with the help of stakeholders are coping with these challenges. It was found that the HIV/AIDS orphans face numerous challenges which are financial, material, and stigma and discrimination related. The implication of this is that, most of them cannot afford to enrol in school, and the few who have enrolled find it difficult to continue with their schooling due to the many stumbling blocks ahead of them. Most of them cannot afford to meet some of their financial and material needs such as payment of school fees, buying of school uniform, books, pens, paraffin and shoes. Similarly, food and medication are some of the challenges they have to battle with on a daily basis. Emotionally, most orphans live without the bare

minimum of love, care and support. Moreover, most of them remain in a state of stress due to the deteriorating health conditions of their sick parents.

As UNAIDS (2002) argued, most orphans begin feeling the impact of the disease even before their parents are dead. This is explained by the fact that, most of them have to go through all the traumatising experiences of seeing their parents' bodies wasting as they reach the advanced stages of the disease. Moreover, this stage is followed by yet another demanding stage where these children, and more particularly the girl child has to begin nursing these sick parents, in addition to taking care of their siblings. The result of this is deteriorating school performance of especially the girl child, as most of their time for studies is robbed away by these domestic chores. In the worst case scenario, some of them end up dropping out of school, while others are forced to opt for sex business as a survival strategy (Germann, 2005; Togom, 2009 and UNESCO, 2010).

However, despite all the afore mentioned, the chapter discussed that, some of the orphans are very resourceful individuals as many of them manage to develop the leja-leja coping strategy where they involved themselves in doing some income generating activities such as, selling water, mangoes, pan cakes, cassava flour and vegetables leaves. Emotionally, some of them sought the services of elders, friends and peers for provision of advice, guidance and counselling. Similarly, most of them used local herbs for treating themselves in times of illness. Furthermore, the chapter also paid attention to, the role played by stakeholders such as IGAD, SSAC, KKLC and other nongovernmental organisations implementing HIV/AIDS programmes in the area. Their role has been found to be of paramount importance in helping the HIV/AIDS orphans cope with their financial challenges. In the same way, the role played by religious leaders and elders in helping the orphans cope with their emotional challenges has been given a due consideration.

Finally, though important stakeholders like teachers and some of the religious leaders have been unable to support the HIV/AIDS orphans cope with their financial challenges, their contribution to the well being of these orphans has been noted with great appreciation considering the fact that most of them acted like parents, guardians and counsellors to these orphans in times of need. Likewise, the infancy of the South Sudan government has been noted by stakeholders as a major reason for its inability to support the HIV/AIDS orphans



cope with their financial challenges. The available documents reviewed, though, showed a lack of prioritization of the education of the HIV/AIDS orphans in particular, and education in general. This may be seen as a factor explaining the apparent lack of government support to the education of the HIV/AIDS orphans. Such a contention has been supported by the continuously dwindling government budget allocated to the education sector vis-à-vis its defence budget (GoSS/MoF&EP, 2010). A further discussion will be done on this same issue in chapter five.

## **Chapter Five: Concluding Remarks**

### **5.0. Introduction**

This chapter presents some concluding remarks on the study that was aimed at exploring the education-related challenges and coping strategies of orphan children in Kajo-keji County, South Sudan. Attention will be focused on discussing the resourcefulness of orphans, the governments' contribution to the education of the orphan children and the changing attitude of family members towards support and care for orphans. The chapter will be concluded by a short summary of potential areas for Action.

#### **5.1. Orphans as resourceful individuals**

The findings of this study indicate that, despite the numerous challenges the orphan children face in meeting their basic needs such as food, education, medical care, clothing and to some extent shelter, which collectively contributed to affecting their schooling experiences, some orphans have remained resourceful. This resourcefulness is attributed to their ability to develop the leja-leja coping strategy which necessitated their physical involvement in doing some income generating activities (IGAs). Some of the IGAs they involved themselves in include, though were not limited to the selling of water, mangoes, pancakes, cowpeas leaves, cassava flour and in some cases engaging in farming activities for some people in return for money. Other coping strategies than the leja-leja coping strategy include the use of local herbs in times of illness, seeking guidance and counselling from adult members of the community and religious leaders in times of distress, and occasionally sharing their problems with their peer members.

Considering the scope of the challenges the orphans go through and the fact that most of the orphans are young children, who cannot afford to meet all their basic needs despite their determination to do so, the role of other stakeholders in helping them in their coping process, became crucial. IGAD, a regional body responsible for dealing with some development challenges among the countries in eastern Africa, is one of these stakeholders. It was found that IGAD, through SSAC and KKLC respectively, was involved in paying the school fees of 80 HIV/AIDS orphans in Kajo-keji County of South Sudan, although the findings also revealed that, this scholarship was not enough to keep the orphans in school as it is only meeting the cost of school fees. In order for the 80 orphans who are on scholarship to meet their scholastic needs such as books, pens, rulers and other school materials such as school

uniform, shoes and paraffin so as to remain in school, they have to get involved in doing leja-leja.

Other than institutions like IGAD, the religious institutions in Kajo-keji have played an equally significant role in meeting the basic needs of the orphans. For example, the Christian community managed to open an orphanage centre which is currently hosting over 100 orphans of all causes. Like the other orphans, the HIV/AIDS orphans in the orphanage centre are receiving the services the centre offers such as the provision of food, shelter, education, medical care and guidance and counselling services. Similarly, the Muslim community occasionally do support the orphans financially, though the support is almost like a drop in the ocean as it comes only twice a year during Idd Al-Fitr and Idd Adoha from the contribution of the believers. Significantly, though, important actors such as the state and the family who are suppose to be playing a significant role in solving the orphans educational challenges are not contributing as they should. The next section discusses the governments' contribution to the education of the orphan children.

## **5.2. The government's contribution to the education of orphans**

The plight of the HIV/AIDS orphans in South Sudan has been increased by the belief among some stakeholders that the South Sudan government is still an infant one and therefore unable to meet the needs of the OVCs in the country. Yet, the findings for this study found that the same "infant government" is able to support some sections of the OVCs in the country, for instance, the families and children of war heroes<sup>10</sup>. According to Director-Ole, a participant in this study, it is revealed that the families of war heroes and their children have been able to get two rounds of support, where in the first round, each family got 4000 Sudanese pounds and in the second round, a family got 2000 Sudanese pounds and yet no such assistance has been extended to the families which have lost their dear ones to AIDS.

A careful study of the GoSS budget from 2007 to 2010 revealed great disparity between the budget allocations for the two commissions established to take care of the two categories of orphans. There is the War Disabled, Widows and orphans commission responsible for the families and orphans of the war heroes, and there is the HIV/AIDS commission responsible

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<sup>10</sup> The term 'war heroes' is used to refer to individuals who have been SPLA soldiers and eventually lost their lives in the 21 years liberation war in the Sudan.

for the HIV/AIDS orphans. Table two (2), below shows the budget allocation to these two commissions.

**Table 2: Budget allocation for War disabled, orphans and families of War heroes and the HIV/AIDS commissions for 2007-2010 in both United States Dollars (USD) and Sudanese pounds (SDG).**

Year	Commissions		Difference
	War disabled, Widows and orphans Commission	HIV/AIDS Commission	
2007	3,000,000 USD	1,000,000 USD	2,000,000
2008	3,000,000 USD	5,000,000 USD	-2,000,000
2009	31,140,678 SDG	4,856,800 SDG	26,283,878 SDG
2010	31,660,000 SDG	7,180,000 SDG	24480000 SDG

**Source:** Secondary field data

From the above data, it is evident that the Government of South Sudan (GoSS) has over prioritised its support to the families and orphans of the war heroes relative to the HIV/AIDS orphans. For example in 2007, the difference in the budget allocation to the two commissions is 2 million US Dollars in favour of the families and orphans of the war heroes, which represents a percentage of 66.7 % for this commission, while only 33.3 % of the total budget is allocated to the HIV/AIDS commission. The same is true in 2009 and 2010. For example in 2009, the war orphans commission got the lion's share of 84.4 % while the HIV/AIDS commission only received 15.6 percent. Though in 2010 the percentage allocation to the HIV/AIDS commission increased to 22.7 %, this is still far less compared to the 77.3 % allocated to the War orphans commission.

This data explicitly shows how the two categories of orphans [those whose parents died in the course of the liberation war and those whose parents died because of AIDS] get different levels of support from the GoSS. Even though the financial year 2008 shows a slightly higher budget allocation for the HIV/AIDS commission, that increment did not have any positive effect on the lives of the HIV/AIDS orphans. Moreover, a critical analysis of the limited amount allocated to the HIV/AIDS commission shows that much of the money goes for payment of staff salaries as opposed to supporting the orphans. For example in 2009, out of

4,856,800 SDG allocated to the HIV/AIDS commission, 2,370,101SDG was spent on staff salaries which is more than 50% of the total amount and 1,683,155 was allocated for capital and only a meagre amount 803,544 SDG was allocated for operations. This seems to imply that it is not only the top planners at the Ministry of finance and economic planning of the Government of South Sudan level who are less sensitive to the plight of the HIV/AIDS orphans, but even those employed specifically to address the challenges of the HIV/AIDS orphans. It can then be argued that if this marginalization of the HIV/AIDS orphans is to be addressed, then a real change of attitude from the people working with them is required. Until this happens, their educational aspirations will remain in jeopardy.

Moreover, the education Ministry of the Government of South Sudan (GoSS) is not any better when it comes to addressing the educational needs of the learners in the Country. From the secondary data reviewed, it seems that support to enhance the education of HIV/AIDS orphans came from two sources. One is from an international NGO called ‘help age international’ which has been able to support 490 orphans between 2008 and 2009 and this was followed by another support in the form of a scholarship to 80 HIV/AIDS orphans from IGAD through the SSAC (UNGASS, 2010) as discussed in the earlier chapters. What seems certain from an analytical point of view, however, is the South Sudan Government’s lack of prioritization of education, leading to continuously shrinking National Education budgets. This is rather alarming considering the potential of schooling for humanitarian development, as demonstrated by the findings of this study where schools were considered as safe havens and places where issues such as stigma and discrimination could be addressed. The government’s lack of commitment is also worrying from the perspective that the current illiteracy rate in South Sudan stands at 85% and the country is in desperate need of skilled manpower to contribute in the development process of the war ravaged nation (UNICEF/GoSS, 2008).

A UNICEF/GoSS study conducted in 2008 argued that:

One of the biggest impediments to schooling in South Sudan stems from the lack of prioritization of education at national level. In spite of the progress made in enrolment and other aspects of education in Southern Sudan, a key sticking point seems to be the government’s reduction of the education budget from \$134,000,000 in 2006 to \$111,000,000 in 2007 and \$100,000,000 in 2008. Yet it is now well recognized that meaningful realization of child rights can only be attainable with the proper allocation of resources for child developmental needs. MOEST budgets are still too low to meet

the school requirements. It certainly stands in the way of implementation of children's rights in general and education in particular (UNICEF/GoSS, 2008, p.29).

The report warns that, unless this anomaly is addressed, the quality of education will continue to suffer and will most likely be followed by a drop in enrolment and a loss of interest in education among parents and communities (UNICEF/GoSS, 2008). The table below shows budget allocation and pupils' enrolment trends in South Sudan from 2005 to 2008.

**Table 3: Budget allocation and pupil's enrolment trends from 2005 to 2008**

Year	Enrolment	Budget Allocation in USD	% of GoSS Budget
2005	343,000	-	-
2006	850,000	134m	10%
2007	1,200,000	111m	7.5%
2008	1,500,000	100 m	6.2%

**Source:** EMIS/MOEST 2007.

As already hinted above, the GoSS budget allocation to education continued to shrink from 134 million USD in 2006 to 100 million USD in 2008, while pupil's enrolment continued to increase from 850,000 in 2006 to 1,500,000 in 2008. In 2005, though there was pupils enrolment of 343, 000, there was no budget allocated to the schools at all, though this can be explained by the fact that the government was still being established in 2005 after the signing of the comprehensive peace agreement (CPA).

However, the most challenging fact to understand as revealed by the statistical information above is the continuously shrinking budget allocation to education against rising numbers of pupils. From the above data, it seems reasonable to contend that if the GoSS wants the orphans who are currently at home to go to school, and to retain the other orphans and most vulnerable children (OVCs) already in school, then it has to increase its budget allocation to the education sector so that it is proportional to the educational needs of this group of learners. This data also reveals the significance of the leja-leja coping strategy in enhancing some of the HIV/AIDS orphans' continuity with their education. Overall, a critical analysis of the above trends seems to suggest that though the orphans are doing their utmost to cope and stay in school, the government is not doing enough on its part. The next section focuses on the family and teachers' changing attitude towards support and care for orphans.

### **5.3. The family and teachers' changing attitude towards support and care for orphans**

This study has brought to light some very interesting data and trends which prompt me to ask vital questions about the country and community in which I grew up and also did this study, questions such as: Is the Kajo-keji society a modern, traditional or a hybrid society? Before these questions can be addressed, it's important to briefly throw more light on what the terms tradition and modernity mean. Renowned scholars such Gyekye, Fleischacker and Giddens have attempted to define the terms tradition and modernity. For example, Fleischacker, cited in Gyekye (1997), defines tradition as "a set of customs passed down over generations and a set of beliefs and values endorsing those customs" (Fleischacker, cited in Gyekye, 1997, p.219). This definition is in line with Gyekye (1997) who in his definition of tradition refers to "the Latin etymology of the word *traditum*, which means, that which is handed down from the past" (Gyekye, 1997, p.219). This means that for a practice to qualify to be called a tradition, it must pass through many generations.

However, Gyekye argues that there is need to amend the definition of tradition offered by the other scholars as that which is 'handed down' or 'passed down' from generation to generation. To him, tradition should be defined as:

...any cultural product that was created or pursued by the past generation and that, having been accepted and preserved, in whole or in part, by successive generations, has been maintained to the present (Gyekye, 1997, p.221).

This means that tradition should not be referred to as something which is simply handed down from one generation to another generation. It should be something which was deliberately created by the past generation, accepted and maintained or preserved over the years by the successive generations to the present generation possibly because of the value a particular society has attached to that particular cultural product. This means that the next generation has the right to either accept or reject the tradition of their fore fathers.

On the other hand, Gyekye argued that the term modernity is etymologically linked to the Latin word *modernus*, a word that medieval scholars derived from *modo*, meaning "just now", "recently" and "present" (Gyekye, 1997, p. 267). While according to Giddens, modernity "is past tradition order, but not one in which the sureties of tradition and habit have been replaced by the certitude of rational knowledge" (Giddens, 2004, p.3), meaning that all what is currently seen as modern has roots in the past. What people have tried to do is

to modify some of the traditional ideas to fit the current circumstances. However, Gyekye himself defined modernity as “the ideas, principles and ideals covering a whole range of human activities that have underpinned western life and thought since the seventeenth century” (Gyekye, 1997, p.235).

In reference to the foregoing discussion on tradition and modernity, it could be argued that many African societies have cherished what is commonly referred to as ‘community culture’ for quite a long time making this prioritisation of communitarianism over individualism traditional. However, the findings of this study revealed that the ‘community culture’ which has been nurtured across many societies in South Sudan and Kajo-keji in particular for many years is fast disappearing. In traditional Africa and in Kajo-keji County in particular, a child, once born, belongs to the whole society and every adult member of the society has a very important stake in ensuring the wellbeing of the child. This practice has provided a safe haven for all orphans because they naturally find themselves fitted in to the family’s extended system. Likewise, from my experience of growing up in this society, a teacher was seen as a mother and a father to every child under his or her care. More so, the practice of sharing whatever little you have was not an issue to be discussed, as it is something which is expected to happen naturally.

However, this study unearthed some interesting trends which tend to contradict the expectations that the traditional African society has of an adult relative, neighbour, teacher or whoever has a stake in the society. It was revealed that it is not uncommon for uncles to refuse care to their nephews who have been made orphans by AIDS, as explained by Coordinator-Ayet and Grand Mama in the findings chapter. It therefore poses the question of whether this behaviour is to be attributed to modernity, selfishness or poverty. Similarly, the art of sharing seem to be disappearing among some of the important stakeholders in our community such as the teachers, as evidenced in an earlier chapter when I asked Teacher-Lokutuk whether he and the other teachers do help the HIV/AIDS orphans when they are in difficult financial situations. As his reply shows, Teacher-Lokutuk felt that there was nothing the teachers could do because their conditions are equally hard.

The investigations from this study indicate that, the few voices above are a representation of the broader picture among the rest of the stakeholders in Kajo-keji County. In order to try and understand the direction in which Kajo-keji society is leading, we could consider what



Snyder and Sherri (2001), for example, have to say about the important differences between a traditional and modern society.

The group is more important than the individual. Individuals identify almost exclusively with their family, clan or caste; they do not see themselves as having an independent destiny apart from the group. People do not feel that they are important individually; they are only concerned about the well being of the group. They care more about pleasing the whole family instead of themselves. While Modern Societies are the opposite; people care more about the individual than the group (Snyder and Sherri, 2001, p.1).

In reference to the fore mentioned trends occurring in the Kajo-keji society, the above argument by Snyder and Sherri seems to suggest that the members in this society are becoming more modern in their behaviour as their focus seems to be more directed to the individual than to the group.

In addition to Snyder and Sherri's, argument, Breidlid (2002), argues that traditional societies tend to be rural, unscientific and show resistance to change, whereas modern societies tend to be regarded as scientific, change oriented, dynamic and urban (Breidlid 2002, p.38). However, Breidlid does not believe that the difference between a traditional and a modern society is black and white. He stresses that, all societies experience change over time, although at different paces (Breidlid 2002). More so, Gyekye (1997) argues that "...modernity unavoidably contain elements that are clearly traditional, inherited and appropriated from previous generations. Secondly, "modernity in its evolution must have elements of tradition" (Gyekye 1997, p.236).

I believe however, that the effect of HIV and AIDS on communities like Kajo-keji has been so rapid and intensive that they have not had time to adapt or may still be in the process of adapting. As a result, I would argue that the individuals of Kajo-keji neither have traditional nor modern behaviour, but rather a hybrid one, in the same way that, the society they live in is neither traditional nor modern, but a hybrid one. This implies that individuals and the community in general will display characteristics of both a traditional and a modern society and sometimes these are contradictory. For example, the attitude of the teachers and the uncles of the HIV/AIDS orphans of doing what satisfy them as individuals while disregarding the society's expectations is a reflection of some elements of a modern society. On the other hand, the positive attitude of people like Grand Mama who generously takes care of the

HIV/AIDS orphans with her meagre resources is a justification that the society still has some elements of traditionalism.

The findings seem to show, though, that where the HIV/AIDS orphans are caught up in these tensions between tradition and modernity, it is the traditional elements which seem most helpful to their plights. The use of traditional herbs and leja-leja strategies as opposed to the apathy of modern institutions of government seems to support this contention. Additionally, the limited assistance from institutions like NGOs and religious organisations can be seen as pointing to the society's hybrid character. The next section provides a brief summary of potential areas for action.

#### **5.4. Suggestions for improvement**

Collective responsibility by all stakeholders in developing working strategies for helping HIV/AIDS orphans cope could be a meaningful solution to the already alarming situation of the HIV/AIDS orphans created by the AIDS pandemic. The government through its relevant ministries can assist through developing appropriate policies, including legal and programmatic frameworks, as well as essential services for the most vulnerable children which offer immediate protection to them and securing their future (UNAIDS 2002).

UNAIDS (2002) further argues that Governments have a crucial role in ensuring children, families and communities are able to cope. This is because governments have signed international agreements and national laws obliging them to take action. Governments facing HIV/AIDS epidemics need to further develop and reinforce laws and policies to protect increasing numbers of vulnerable children. Moreover, they need to implement and enforce these policies through ministries, agencies and other governmental structures. Governments also have ultimate responsibility to ensure that children who fall through the safety nets of both family and community are protected and have access to essential social services. The governmental response to children affected by HIV/AIDS must be multi sectoral and integrated with basic health, education, and development programs (UNAIDS, 2002).

It further suggests that, strategies for governments to pursue include: developing national action plans to guide programming; reviewing, strengthening, and developing child law and protection services; and strengthening delivery of education, health, and other essential

services. It cautions that, these efforts require widespread governmental collaboration with international organizations, donors, NGOs, religious groups, community associations and the private sector. It further emphasises that though Governments may not have sufficient funds to provide all necessary services, they do have the capacity and the mandate to bring together stakeholders so that each can contribute to a collaborative national effort (UNAIDS, 2002).

Religious institutions can play a major role in changing the general perception of the population about AIDS and the challenges it poses to both the infected and the affected through conducting mass mobilisation together with other stakeholders like journalist. Effective public information and social mobilization can accelerate change so HIV/AIDS evolves from ‘their problem to our problem’. Furthermore, religious networks can as well be influential in urging a compassionate response to people impacted by HIV/AIDS (UNAIDS, 2002).

In addition, the importance of teachers in helping HIV/AIDS orphans cope with their challenges should not be under estimated. For example, in the absence of parents, the school can be seen as the most important agent in addressing the needs of vulnerable children. For instance, planning a curriculum that addresses the needs of these vulnerable children will have to be reconsidered and at the same time, the full impact of the diversity of learners and their communities will have to be accommodated in all planning. All this is done with an attempt to prepare an accommodative learning environment for these HIV/AIDS orphans to enable them lead a normal life like any other child in the school (De-wit, 2007). In addition, teachers may also be tasked to introduce life-skills–based education in schools with an objective of making children know the dynamics of the epidemic. This initiative does not only enrich knowledge but also encourages young people act as change agents while participating openly as peer educators in community-based activities (UNGASS, 2010).

Likewise, HIV/AIDS orphans need to be assisted to cope with their challenges so that amidst all the ups and downs on their way, a brighter future can be shaped for them. UNAIDS (2002) argued that HIV/AIDS catches children in a double bind in a way that, they must support both themselves and their families, often under the pressure of serious poverty, yet many are forced out of school just when they most need to prepare for their own futures.

It further argued that, keeping vulnerable children in school is the first line of defence. This provides them a secure environment to learn skills that will help them provide for their own needs as they grow into adulthood. More so, interventions must address key factors that fuel the dropout rate; for instance school expenses, caring for relatives, and compensating for lost income. Overall, it is important to recognize that young people are not the problem, but an essential part of the solution. Support for them as they plan and carry out solutions to meet their needs is crucial and this should go beyond addressing the impact of HIV/AIDS to preventing infection (UNAIDS, 2002).

More so, all existing community structures need to be strengthened to develop more pragmatic ways of looking at the problems of the HIV/AIDS orphans so that instead of raising these orphans in orphanage centres which tend to affect their ability to integrate into the community in the future, family support systems could instead be encouraged which could help their socialisation and yet be less costly.

I conclude this chapter by citing this important remark from Lomole, who is one of the HIV/AIDS orphan and a participant in this study who lamented that:

If I had someone to support me, I would like to work very hard in school so as to become a medical doctor in the future. This is because; life in our community is not good. Health conditions like that of my mother would have been easily handled if there were medical doctors (Lomole, a 13 years old, primary 3 pupil).

This remark still point to the resourcefulness of the orphans. Lomole is one of the HIV/AIDS orphans who has already lost his father to AIDS and is nursing the sick mother. From his argument above, he is not only aspiring to better his own life in the future, but that of his family and the community at large. Such arguments present a very strong case to why these orphans should be supported in achieving their educational aspirations.

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## **Appendices**

### **An interview guide for Pupils (orphans), Head teachers, teachers, religious leaders, elders and Directors**

*Note: Every interview will begin with an introduction. I will begin by fully introducing myself to the interviewee and also request the interviewee to do the same.*

#### **Interview guide for the County Education Director**

- a. Number of orphans in the county
- b. What is the actual number of boys and girls

#### Government policy on orphans

- a. What is the government policy on the education of orphans?
- b. How is it implemented? Are there any challenges to the implementation?
- c. Does the county extend any support to the orphans? If yes, what kind of support? If no, why?

#### **Interview guide for the county Director of Health services**

- a. What is the number of HIV positive persons in the county? Could you clarify the number of adult males and females?
- b. Do you have any record of how many who have already died of the disease and how many are on Anti-retroviral treatment?

#### Government policy on the infected and the affected

- c. Does the Ministry of Health have a particular policy on HIV/AIDS treatment and care for the infected and the affected?
- d. What would you describe as the challenges of implementation of this policy?
- e. Does your department support those who are infected? If yes, in what ways?
- f. What about the orphans. Is there any support you extend to them? If yes, what kind? If no, why?

### **Interview guide for Head teachers**

- a. Do you have orphans in your school? If yes, how many? Could you break that total in terms of boys and girls?
- b. What is your general view about these orphans in terms of:
  - 1-School attendance. Do they attend regularly? If no, what do you think could be the reasons? Have some of them one day come to your office to explain to you why it is not possible for them to come to school early? Could you share the main points of your discussion with me?
  - 2-Their relationship with the teachers and the other pupils?
  - 3-Payment of registration fee, PTA fund or development fund
  - 4-Following of school norms. For example, coming to school in school uniform.
  5. Performance in test and exams?
  - 6- Do you see some or all of them experiencing difficulties in some or all the above areas?
  - 7-Has the school attempted to address them or no? If yes, how? If no, why

### **Interview guide for teachers**

- a. How many orphans do you have in your class?
- b. Could you share with me your experiences with them? Particularly, if you compare them to those who are not orphans, how are they faring in the following areas
  - 1-Performance in class exercises, tests and exams. Is it the same with the rest or no?
  - 2-If not, what particular challenges do you think they face which hinders them from performing like their peers?  
Relation between teachers and orphans
- c. I will get most of the information for this section through observations, but I will also endeavour to seek the teachers' general impression
- d. How about punctuality in class, doing of home work and participating in group or class activities. I will get answers for these issues through observations, but will also seek the teachers opinion
- e. Do you help those orphans who face difficulties in your class? If yes, how? If no, why

## **Interview guide for pupils/orphans**

### Feelings about school

- a. Do you enjoy/like school? If yes, why? If no, why

### Homework

- a. Do your teachers always give you some home work?
- b. Are you always able to do your home work? If yes, what motivates you to doing it? If no, what makes it difficult?
- c. Do you study at home after school? If yes, do you enjoy it and what makes you to enjoy reading at home? If no, why?

### Payment of registration fee, PTA contribution, development fund and school uniform

- d. Have you already paid your PTA, registration fee and school development fund? If yes, how easy was it for you to get the money? Did somebody help you with or you got it yourself and how? If no, why?
- e. I will see if the child has put on school uniform. If is without, I will as for the reasons

### Relationship with teachers and fellow pupils both inside and outside the class room

- a. I will get much of the information about this sub-section through observations, though I will also seek to find out the child's general opinion

### Income generating activities (IGAs)

- a. Do you do some small business for getting some money? If yes, how is it helping you both at home and in meeting your school needs? If no, how do you get your food, paraffin, soap, and all those things which needed to be bought from the market?

## **Interview guide for religious leaders**

- a. Do you have orphans who are members of your church/mosque? What about in the whole parish/area under your care? If yes, do you visit them? And how frequently?
- b. From your observation and experience with them, are they living a happy life or are there some particular difficulties they face?

- c. Have you tried to help some or all of them from those difficulties/challenges? If yes, what kind of help have you given? If no, why?
- d. What plan does the church/mosque have for improving the lives of the orphans?

**Interview guide for elders and other stakeholders**

- a. How many orphans are you taking care of?
- b. When did you begin taking care of them?
- c. How are you getting on with them in terms of meeting their school needs and food?
- d. If there are difficulties in meeting their school needs and food, what plans have you developed to address the above challenges/difficulties? Do you involve them in developing the plans and in practically addressing the above challenges?
- e. What is their relationship with the children from the neighbourhood like?
- f. Do they interact/play freely with them or there are some days when the other children avoid playing with them or making life generally difficult for them?
- g. If there are difficulties in their relationship, have you tried to address them? How



## List of Participants

1. Pitet- A 16 years old female HIV/AIDS orphan in p.7
2. Yatet- A 15 years old female HIV/AIDS orphan in p.7
3. Lomole- A 13 years old male HIV/AIDS orphan in p.3
4. Nyaret- A 13 years Old female HIV/AIDS orphan in p.4
5. Busan- A 13 years old female HIV/AIDS orphan in p.3
6. Taling- A 15 years old male HIV/AIDS orphan in p.6
7. Yenet- A 15 years old male HIV/AIDS orphan in p.6
8. Madut- A director
9. Ole A director
10. Malual A Male deputy Head teacher
11. Golyan A male head teacher
12. Lokutuk A male teacher
13. Nyadeng A female project coordinator
14. Florence- A senior woman teacher
15. Ayet A coordinator-female
16. Deborah A project officer
17. Piting A project officer
18. Melesuk Medical staff
19. Salam A male religious leader
20. Yupet A male religious leader
21. Yaba An elder
22. Kudot A male project officer
23. Gordon A male project officer
24. Jabata A male HIV/AIDS project coordinator
25. Malia A female participant
26. Jackline A female project officer
27. Yokoju A male director
28. Tabita A senior woman teacher
29. Deng A male teacher
30. Oleyo A female teacher
31. Abraham A male director
32. Kulang A male teacher
33. Grand Mama A 50 years old woman
34. Ezbon A teacher

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